

**Effects of a structured communication strategy on
anxiety, uncertainty and satisfaction with care in
families of critically ill adults**

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DECLARATION

Statement of Original Authorship:

The work contained in this thesis has not been previously submitted to meet requirements for awards at this or any other higher education institution. To the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made.

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ABSTRACT

Background: The sudden and unanticipated admission of a relative to the intensive care unit (ICU) is both a frightening and stressful event for their families. Family members are affected both physically and psychologically by their experience of having a relative admitted to ICU. Clinical practice guidelines recommend that high-quality care requires focussing on the family, identifying their needs, understanding their experience and implementing effective interventions for supporting them throughout their relative's critical illness.

Communication with ICU staff and families has been identified as one of their most important needs. Inadequate, inconsistent and poor-quality communication has been consistently associated with psychological distress and dissatisfaction with care and decision-making in families of critically ill adults.

Aim: The aim of the study was to evaluate the effects of delivering a structured communication strategy on anxiety (state and trait), levels of uncertainty, and satisfaction overall with care and decision-making in families of critically ill patients who survive ICU.

Two research questions were identified to address this aim:

- In family members of ICU patients, how did the control group and intervention group's state and trait anxiety, uncertainty in illness, and satisfaction overall with care and information/decision-making, change from relative's admission to ICU to discharge from ICU?
- What effect did the introduction of the intervention (i.e., communication strategy) have over time on the intervention group compared to control

group ICU family members state and trait anxiety, uncertainty in illness, satisfaction overall with care and with information/decision-making (time x group effect)?

Methods: This was a quasi-experimental study with a pre-and post-test non-equivalent control group design. Family members in the intervention group ($n=26$) received both oral and printed information to guide them in preparing for a structured family meeting. The family members allocated to the control group ($n=26$) received usual routine care, and experienced the existing family informational support already operational in the study site ICU. State and trait anxiety, uncertainty, family satisfaction scores overall with care and information/decision-making, were measured in the two groups within 48 hours of ICU admission, and prior to ICU discharge.

Results: Following the intervention, the experimental group reported lower state anxiety and uncertainty scores, but these failed to reach a level of significance ($p>0.05$). Both groups of family members were highly satisfied overall and with care in the ICU (>80%). Families were mostly, rather than highly, satisfied with information and decision-making (73% versus 71%). From the three free-text responses introduced on the FS ICU questionnaire, family members reported the largest number of negative comments for frequency of communication with medical staff and the ICU waiting room.

Conclusion: Structured oral and written communication reduced anxiety levels in families of patients admitted to the ICU, although this reduction was not significant or exclusive to the intervention group. Uncertainty levels reduced in those receiving the intervention, this reduction was not seen in the control group.

Families were highly satisfied overall, but improvements could be made with the frequency of communication with medical staff and inclusion and support in the decision-making process.

More studies are needed into the effectiveness of interventions in ICU, and their core components to help improve family members' satisfaction with care, and their psychological health and well-being. Intensive care units that are able to support interventions based on meeting family information needs, in addition to reducing psychological burden and dissatisfaction, will enable each family to provide more support to their relative within the ICU.

Keywords: Family, intensive care, satisfaction, needs, interventions, anxiety and uncertainty

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CHAPTER 1: INTRODUCTION

1.1: Background: Rationale for the study

This section outlines the rationale for this study and the overall organisation of the thesis. This thesis evaluates the effects of delivering a structured communication intervention on state and trait anxiety, levels of uncertainty, and family satisfaction overall with care and decision-making, in family members of the critically ill. This area of research was selected as the entirety of my clinical experience has involved caring for the critically ill adult. I also hold a psychology honours degree and have always had a keen interest in the psychological sequel, not only for the critically unwell patient, but also the impact that it has on their families.

In Scotland, 46,166 patients were admitted to the ICU in 2018. This figure increased slightly to 46,288 in 2019 (Scottish Intensive Care Society Audit Group, (SIGSAG) 2019, 2020). Of these patients admitted to ICU, 17% died before hospital discharge in 2018; this figure increased to 18% in 2019 (SIGSAG 2019, 2020). It is well documented within the literature that many patients admitted to the ICU come without warning, and their physiological condition is unstable and unpredictable (Williams 2005). This unanticipated event for a relative in a critical clinical state can be particularly frightening and stressful for their families.

Initially, I introduced the Confusion Assessment Method for ICU (CAM-ICU) tool for diagnosing delirium into my clinical practice (Scott, McIlveney and Mallice 2013). Following this, I developed the ICU discharge liaison service, recognising that, although patients were ready for transfer out of the ICU, they remained the sickest group of patients in the hospital, transitioning from a highly technical

environment to a less acute clinical environment. The goal in providing this service was to offer clinical expertise to the ward medical and nursing staff in order to continue to deliver high-quality care to these complex patients, whilst providing emotional support to the patients and their families as they make the transition from ICU to ward-based care, and then subsequently to be discharged and return home.

My clinical experience of follow-up led to the implementation of the three-monthly ICU patient and family support groups and six-monthly ICU outpatient clinics. Whilst all transitions from ICU to different points of care are challenging, for patients who are discharged home after surviving critical illness, this is particularly difficult. Patients and their families have multi-faceted problems related to their ICU experience. These post-discharge services provide an opportunity to discuss with the patient and their family members what they should expect from their recovery, and, for the ICU team, to listen to their lived experiences of critical illness. It was through listening to these patient and family stories, coupled with my own experience of working with families daily in clinical practice, that I was guided towards this clinical doctorate study.

Family members of ICU patients face a crisis period, invoked by their relative's admission to a clinical area known for its intensive medical interventions and relatively high mortality rate (Azoulay et al. 2005). They are initially shocked and confused by the gravity of the situation, struggling to understand what has suddenly happened. Research suggests that they are frequently overwhelmed by feelings of anxiety and worry, due to the fear of losing their loved one, and deterioration of the family structure, combined with the stressful technological

ICU environment (Bijttebeir et al. 2001, Delva et al. 2002, Johnson et al. 2019). Feelings of uncertainty regarding their relative's condition, treatment and care, further reduces their adaptation to the illness event and their ability to cope effectively with the crisis of a serious and potentially life-threatening illness (Mishel 1988). Psychological symptoms may be time-limiting for some family members, but, for others, they experience psychological distress that persists for months to years after hospital discharge, which influences both their quality of life and lifestyle (Paul and Rattray 2008, McPeake et al. 2016, Johnson et al. 2019).

Clinically, as a senior charge nurse working in ICU and through my experience, the anxiety and uncertainty that these families experienced as they waited for both information on their relative's condition and patient contact was very noticeable. For example, during what may seem to be a short period of time for the ICU team at the study site, I would at times be informed directly, or hear family members express to the bedside nurse, that they were left for long periods of time, did not know what was happening, and that they just wanted to see that their relative was safe.

In general, in the ICU setting at the study site, there was a relatively unstructured approach to family communication, no formal recommendations or structured processes were in place. Communication most frequently occurred in a more casual format when family members were present at the bedside, but this has been reported to carry the highest risk of miscommunication, as less preparation is carried out (Pauldine and Doramn 2013). I was keen to explore which interventions were available that involve both nursing and medical ICU staff to

provide a more robust and consistent structure to family communication, and one which could also improve psychological outcomes for family members whose relative survives ICU. I specifically chose to focus on families of ICU survivors, because those were the cohort of family members who at follow-up explicitly described to me the difficulties, especially around communication, that they experienced within the ICU. Furthermore, family members who survive ICU are at increased risk of psychological symptoms and are less satisfied with family communication (Azoulay et al. 2005, Wall et al. 2007).

This study was conducted prior to the current coronavirus (COVID-19) pandemic. This disease has spread to 188 countries/regions with more than 154,513,735 confirmed infections and 3,231,054 deaths globally, of which the United Kingdom (UK) has seen 4,441,638 confirmed infections and 2,609 deaths, a figure which at present continues to rise (John Hopkins Coronavirus Resource Centre 05th May 2021). As a result, the Scottish Government had initially required to “lock down” the country, where only essential employees were allowed to work, and family members were not allowed to visit any hospital wards, inclusive of ICU. As “lock down” eases, family visiting remains severely restricted, due to the risk of ongoing infection to themselves and to healthcare staff. As such, the clinical implications of family absence in the context of this ICU study site’s intervention and the alternative approach to family communication during the COVID pandemic is also discussed in this thesis.

An overview of the thesis format now follows.

1.2: Thesis outline

The structure of this thesis is outlined and sets the scene for the area of research that follows. This thesis is organised into eight chapters. **Chapter 1** introduces the topic and rationale for the study, based around existing literature and my own clinical experience.

Chapter 2 consists of a scoping review of the relevant literature, comprising four key themes emerging from the evidence, which include: different perspectives on meeting family need, family satisfaction in ICU, factors having an impact on family well-being and their capacity to cope, and psychosocial interventions (see published paper, **Appendix I**). This leads to the aim and main research questions being identified.

In **Chapter 3**, the chosen research methodology and methods are explained, and a rationale for adopting the quasi-experimental approach. This is followed by an overview of the study sample, data collection and analysis processes. Ethical considerations and measures undertaken to maintain ethical principles during the study are described.

Chapter 4 evaluates the family communication intervention used in this study (family meeting toolkit) proposed by Nelson et al. (2009). This includes a description of the modifications made following feedback from the study site's medical and nursing staff and ICU family members, and then the pilot testing process prior to completing the final study.

Chapter 5 presents the results of the study related to the two main research questions. In addition, the findings from the qualitative comments from the three

free-text questions provided by the family members on the FS-ICU questionnaire (Heyland and Tranmer 2001) are reported.

Chapter 6 provides the main discussion for the thesis and synthesis of all of the results. Further theoretical discussion is presented in **Chapter 7**, which explores the results within Mishel's (1988) Uncertainty in Illness theory.

Chapter 8 concludes the thesis, considers the strengths of the study, and recognises the limitations of the study. Recommendations for clinical practice and future research in light of the recent COVID-19 pandemic are made.

CHAPTER 2: LITERATURE REVIEW

2.1: Introduction

The current literature primarily focuses on healthcare professionals' knowledge and understanding of ICU family needs (Verhaeghe et al. 2005). It provides little insight from the perspective of the family as to what their experiences are, how they perceive the care delivered, and the impact of having a loved one in ICU. There is limited research describing family experiences whilst in ICU, and very few reports of structured interventions that might support them from the time of their relative's admission through to their transition to ward-based care. Specifically, for those family members whose relative survives ICU, the evidence is scarce.

This scoping review was undertaken to inform the development and design of this study. The relevant literature included in this review was identified through a systematic approach, informed by Arskey and O'Malley's (2005) scoping review framework. The scoping review is becoming an increasingly popular approach for synthesising research evidence in healthcare (Davis et al. 2009). It is a specific method that aims to "map the literature" on a topic of interest, identifying areas which have been well explored, whilst highlighting areas that still require exploration (Arskey and O'Malley 2005, Tricco et al. 2016).

Similar to systematic reviews, scoping reviews use rigorous and transparent methods to analyse literature pertaining to the search questions (Arskey and O'Malley 2005). However, there are several key differences between the two. These can be attributed to, firstly, that systematic reviews evaluate a narrow range of studies to answer focussed questions of effectiveness, while scoping

reviews have a broader mandate to examine the range and extent of research activity in a particular field (Levac et al. 2010). Secondly, scoping reviews include a greater range of study designs and methodologies than do systematic reviews, which mainly focus on randomised controlled trials. The scoping review was considered an appropriate approach for this study and presents a broad overview of published works related to the experiences of family members whose relative survives ICU. This specific method allowed for the inclusion of a wide range of study designs, particularly in this area of emerging evidence, which had not yet been comprehensively reviewed.

The method adopted for this scoping review was informed by the five-stage methodological framework, as outlined by Arskey and O'Malley (2005), which was to: 1) identify the search questions, 2) identify the relevant studies, 3) perform the study selection, 4) chart the data, and 5) perform the data collection and reporting of the results.

2.2: Identifying the search questions

The broad scoping review questions set before the literature search were as follows:

- 1) What is currently known about family needs and experiences of ICU survivors?
- 2) What were the psychological symptoms experienced by these family members in the ICU and the interventions available aimed at reducing those symptoms?

2.3: Identifying relevant studies

To identify articles for this scoping review, a literature search on families of critically ill adults who survive ICU was undertaken. The search strategy involved searching the following databases: Medline, CINAHL, Embase, PsychInfo, Science Direct, the Cochrane Library of Systematic Reviews, and Google Scholar. The terms used to search the electronic databases were a combination of: **Adult critically ill and/or Intensive care patients, family needs, family satisfaction, family meetings, communication interventions, anxiety and uncertainty.**

2.4: Study selection

Studies were selected using specific inclusion and exclusion criteria (**Table 1**). Studies focussing solely on end of life were excluded as the intervention in this study was aimed at family members of the critically ill who survive ICU. Paediatric or neonatal patients were also excluded as the focus was on family members of adults with critical illness. Only papers that were published after 1975 were considered for inclusion as the first seminal study by Hampe was published that year.

Table 1: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Publications on family members of adult critically ill patients admitted to the intensive care unit	Paediatric or neonatal ICU setting
Publications between 1975 to 2021	Relative involved at end of life, e.g., withdrawal of treatment, brain stem death or organ donation
Publications in English	Published in language other than English

Both qualitative and quantitative studies were included to facilitate greater understanding of the evidence about ICU family members' needs, experiences, and interventions to improve their psychological health and well-being. Determining which studies to include in the scoping review was an iterative process. A three-step approach to selecting the relevant articles was employed. At first, titles and abstracts were examined by the author to identify publications that met the inclusion criteria and the extent and ability of each study to answer the search questions. Secondly, this search was supplemented by scanning reference lists of review articles, and eligible primary studies were checked to identify cited articles not captured by electronic searches. Thirdly, all final papers underwent two independent reviews, one by the author and one by a study site ICU clinician, to confirm whether the study met the inclusion criteria. There was full agreement regarding the papers for inclusion. However, should there have been a disagreement, a second ICU clinician at the study site was available to review and decide on inclusion.

2.5: Presenting and charting the data

A total of 465 published papers were initially retrieved. Removing duplicates and screening abstracts resulted in 61 published articles, which included 57 empirical studies, three literature reviews, and one systematic review. A flow chart was generated to indicate the papers included in the review that met the inclusion criteria, which followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines **Figure 1** (Liberti et al. 2009). The relevant articles were included for data extraction and obtained in full-text format for further examination.

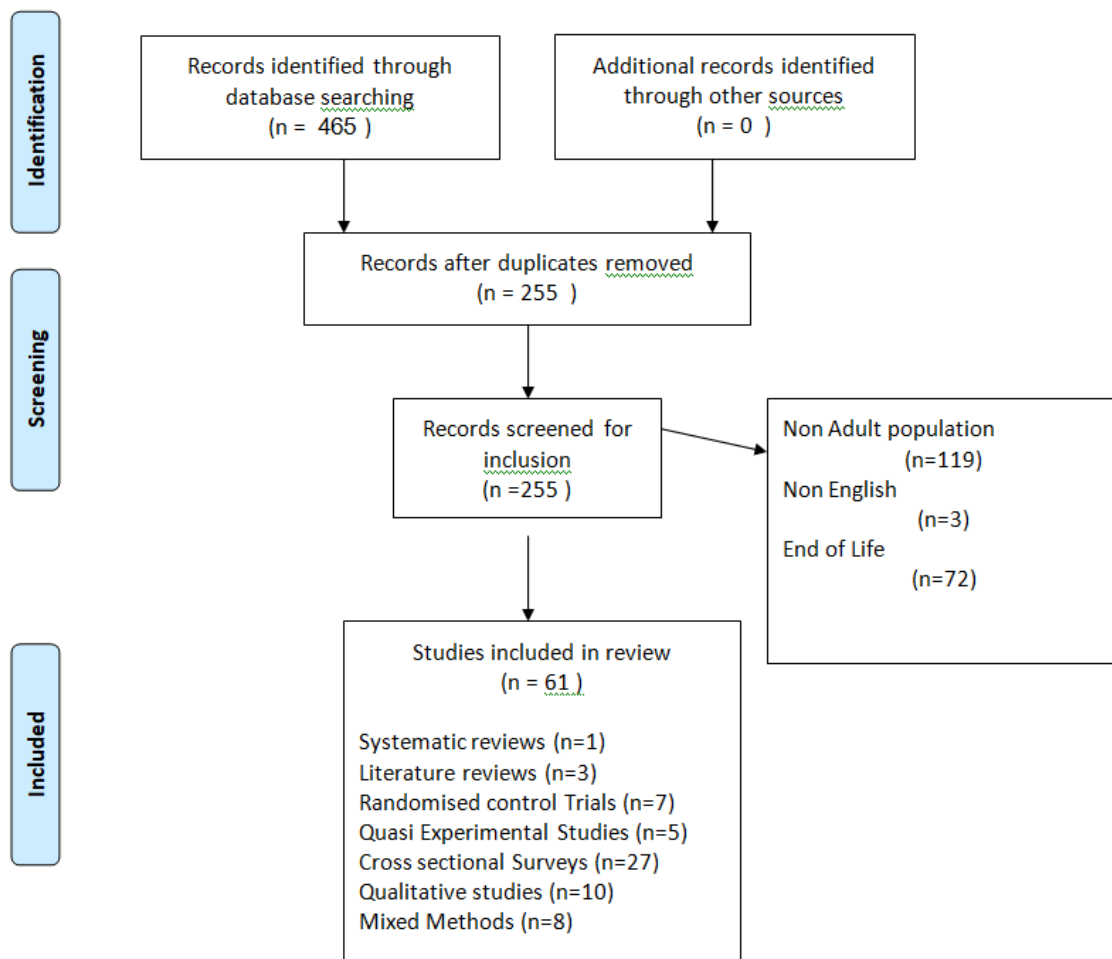


Figure 1: PRISMA flow diagram of literature screening

To enable a logical and descriptive summary of the results, data extraction sheets were completed for all papers and presented using the following key headings: author(s), year of publication; study aim; study setting, country of origin; sample size; study design; and outcome (**Appendix II**). This data extraction tool was designed to chart specific details of the literature to help gain an understanding of family members' experiences in the ICU.

Studies relevant to the review were assessed for quality using the Joanna Briggs Institute Critical Appraisal Checklist data tools for qualitative, cross-sectional, quasi-experimental or randomised controlled trials, dependent on study design (Joanna Briggs Institute 2017). Articles were appraised against the questions

asked, to identify the strengths and weaknesses of the selected articles. An example of the checklist used for the cross-sectional studies is provided in **Appendix III**.

2.6: Data collection and reporting the results

Following data extraction and quality assessment, the resulting quantitative research studies included seven randomised controlled trials, five quasi-experimental studies, and 27 cross-sectional surveys. The qualitative research included three grounded theory studies, one focus group study, and six other studies that employed a qualitative approach, although no specific design was specified. A further eight studies used a combination of quantitative and qualitative approaches (mixed methods). **Table 2** outlines the origin of the published papers retrieved; most studies were aimed at the nursing profession, and were conducted in the United States of America (USA) and within a general ICU setting.

Table 2: Origin of published papers

Published Source	No. (61)	Country of origin	No. (61)	ICU setting	No. (61)
Nursing	35	Oceania		General ICU	56
Medical	23	Australia	6	Neurological	4
Psychology	1	North America		Medical ICU	1
Pharmacy	1	USA	17		
Social Work	1	Canada	4		
		Asia			
		Hong Kong	3		
		Malaysia	1		
		Korea	1		
		Europe			
		United Kingdom	6		
		Scandinavia	6		
		France	5		
		Belgium	3		
		Greece	3		
		Spain	1		
		Turkey	1		
		Germany	1		
		Middle East			
		Jordan	1		
		Iran	1		
		Egypt	1		

2.7: Identified themes

Initially, each data extraction sheet and paper was read and re-read to achieve familiarisation of the data (**Appendix II**). Existing literature from empirical studies by Hampe (1975) and Molter and Leske (1983) were reviewed first to uncover already existing categories. The results sections were read many times, asking: “What is currently known about family needs and experiences of ICU survivors?” and “What are the psychological symptoms experienced by these family members in the ICU and interventions available aimed at reducing symptoms?”

Key themes, based on these results and reflecting my knowledge of this field, were emerging.

The synthesis of the literature in this review highlighted what family members' needs and experiences were following admission of a family member to ICU. Four key themes relevant to the scoping review questions were prominent and related to: 1) Perspectives on meeting family need, 2) Family satisfaction in ICU, 3) Factors impacting on family well-being and capacity to cope, and 4) psychosocial interventions. No outliers were found, as all findings in the literature fitted well within these final four themes.

The following is a descriptive summary of included papers with a narrative synthesis of existing relevant literature, presented under these four main themes identified from the scoping review and recently published in *Nursing Open* (Scott et al. 2019; see **Appendix I**). Evidence for each of these themes is discussed below, but, prior to this, the integral role that families play in the ICU is discussed.

2.8: Family-centred care in ICU

2.8.1 Definition of family

In the past, the word "family" meant a legal relationship created by blood, legal ceremony or legal adoption (Herring 2014). Through changes in society, this definition has also changed and the meaning of family and the circle of family members has broadened over the years. The United Kingdom Office of National Statistics defines "family" as: a married, civil partnered or cohabiting couple with or without children, or a lone parent with at least one child, who lives at the same address (Office of National Statistics 2021, p. 2). Clinical practice guidelines define family as being "defined by the patient or, in the case of minors or those

without decision-making capacity, by their surrogates, who may or may not be related” (Davidson et al. 2017, p. 55).

Identification of a representative sample of ICU family members is clearly critical to reliable and generalizable findings in ICU family research studies. In line with current definitions of family, investigating all family members available during a patient’s stay would be one option of investigating family satisfaction and psychological symptoms in this study. Another option would be to identify a “primary” family member with the highest relationship to the patient, using first-degree relatives rules (Lautrette et al. 2007).

Clinical studies that have examined state and trait anxiety symptoms, family satisfaction and uncertainty, have predominantly recruited first-degree relatives in identifying a primary family member (Appleyard et al. 2000, Mitchell and Courtney 2004, Johansson et al. 2005, Chien et al. 2006 Paparrigopoulos et al. 2006, Ågård and Harder 2007, Hendrich et al. 2011, Karlsson et al. 2011, Hunziker et al. 2012). Accordingly, the use of the first-degree relative was the preferred inclusion and exclusion criteria for use in this study, and one to which the nursing and medical colleagues working at the study site readily relate.

2.8.2: Definition of family-centred care

The clinical condition of patients admitted to the ICU and their inability at times to communicate, due to severity of illness or sedation, means that the ICU team caring for these patients are also caring for their family too (Mitchell et al. 2009). Family members therefore have a pivotal role to play when their relative is admitted to the ICU. Clinical practice guidelines define family-centred care in neonatal, paediatric and adult ICUs as an “approach to healthcare that is

respectful of and responsive to individual families' needs and values" (Davidson et al. 2017, p. 55). This approach requires that the patient's family participates and collaborates with healthcare professionals as partners in care.

Family-centred care (FCC) has expanded rapidly over recent years, and providing high-quality FCC has been identified as a basic skill for ICU medical and nursing staff (Gerritsen et al. 2017). The most recent family-centred care guidelines, published by the Society of Critical Care Medicine, based on rigorous analysis of evidence concerning the role of families in ICU care, make recommendations in five key areas for FCC: 1) supporting family presence in the ICU, 2) family support, 3) strategies to improve communication with family members, 4) use of specific consultations and ICU team members (palliative and ethical), and 5) operational and environmental issues (Davidson et al. 2017). These guidelines represent the current state of international science in family-centred care and of providing support for family members of critically ill patients, irrespective of the patient's age.

Families are more than just visitors to the ICU; they expect to experience the same process of care as their relatives. ICU healthcare staff should therefore incorporate them into the provision of critical care (McAdam and Puntillo 2009). They are, however, a vulnerable group, with a high risk of decline in their own health (Baumhover and May 2013). The sudden change in their everyday lives, coupled with being in a stressful, unfamiliar and technical environment with frequent changes of staff, can lead them to become confused, anxious and uncertain (Bijttebeir et al. 2001, Delva et al. 2002, McAdam and Puntillo 2009).

2.8.3: Shared decision-making in the ICU

According to the principles of patient autonomy, healthcare decisions involving serious interventions should be based on informed consent (Patient Rights (Scotland) Act 2011). However, because most ICU patients cannot make decisions on their own medical treatment, the family may be requested to make difficult treatment decisions on their behalf (Maxwell et al. 2007). Subsequently, when a relative is critically ill, complex and often urgent decisions are required to be made, placing additional pressure on these family members and heightening their emotional needs (Azoulay et al. 2014). For these reasons, clinical discussions and decision-making in the ICU should occur through a collaborative partnership process, involving families, ICU nurses and medical staff.

The ICU team and families need to work together, where families contribute as much as they can, whilst receiving guidance from the ICU team (Azoulay et al. 2014). They really require becoming active partners in decision-making when planning their relative's care and treatment (Davidson 2009). This partnership approach to decision-making is not intended to remove control from patients who are competent to make decisions regarding their health, but, essentially, it enables family members to be involved in care and to assist with decision-making when necessary (Institute of Medicine 2001).

Involving the family in the decision-making process does, nonetheless, raise complex challenges. Families do indeed express a desire for being engaged in partnership and joint decision-making, but not necessarily increased responsibility and autonomy (Heyland et al. 2003). Clinicians consider FCC as delegating more responsibility to families for care and decision-making than

families desire. Some family members prefer to discuss decision-making responsibility with the ICU team, whereas others are satisfied that they have been provided enough information and support for decision-making (Heyland et al. 2003). Also, certain family members may not be comfortable acting as a primary decision-maker (Azoulay et al. 2014). Family members' own individual characteristics, such as coping strategies and past experience, can be important factors to consider; those who have been in a similar situation and acted as decision-makers previously may find it easier than those doing it for the first time (Azoulay et al. 2014). In addition, the decision-making process fluctuates throughout their relative's ICU journey. It is therefore dependent not only on their own decision-making capacity and individual preferences, but also on the clinical condition of their relative at that particular point in time (Heyland et al. 2003, Azoulay et al. 2014).

Furthermore, family members may consciously or subconsciously make decisions without having a clear understanding of what is at stake (Azoulay et al. 2003). It is not surprising then that acting as surrogate decision-makers can contribute further to significant psychological burden and distress (Pochard et al. 2001, Paul and Rattray 2008, McPeake et al. 2016, Johnson et al. 2019). Thus, it is important that decision-making involves clinicians actively assessing how involved each family member wants to be, and their understanding of this, so as to support rather than add to their distress during this difficult time (Curtis and White 2008).

2.8.4: Summary

Through changes in society over the years, both the meaning and the group relating to family has expanded. Family is perceived as having a special bond which connects particular people, and this bond can be either law or blood related. Through critique of the ICU family studies, this study focussed on those with the highest relationship to the patient, and thus the recruitment of a first-degree family member was the preferred choice.

Family-centred care in the ICU is very much focussed on the family, creating a partnership and an environment that supports family engagement, which encourages the participation of the family in the decision-making process. Current international FCC clinical guidelines provide the best available evidence to guide ICU teams in providing FCC (Davidson et al. 2017). However, reported barriers to the implementation of FCC include a lack of knowledge, support, and resources for ICU medical and nursing staff, and health professionals' attitudes (Gerritsen et al. 2017). Gerritsen et al. (2017) suggested that, to overcome these barriers, each ICU should decide which FCC recommendations suited their current practice and current outcomes, and which lie within the resources that they have available.

2.9: Perspectives on meeting family needs

To facilitate a family-centred approach, it is necessary to primarily identify family needs and assess how best to meet these needs in the ICU. The emphasis on 'family needs' research has focussed on three areas: 1) The family members' perception of their needs, 2) The ICU team's perception of family needs, and 3)

the ICU staff's ability to meet and satisfy these needs (Hughes et al. 2005). Each of these areas will be discussed consecutively below.

2.9.1: Family members' perception of needs

Hampe (1975) was the first to qualitatively investigate the needs of ICU families by interviewing 27 wives of critically ill patients (who subsequently had died), to determine what their needs were and which of their needs were and were not being met. The identified needs of the grieving wives were divided into two broad categories: 1) needs related to the relationship with the patient, and 2) the personal needs of the wives, which were subdivided further into physical and emotional needs. Hampe (1975) identified several needs that were insufficiently met. The need to know that the patient was emotionally and physically as comfortable as possible was met in less than 33% of cases. The information given was satisfactory in fewer than 50% of the cases, and in only 40% to 45% of the cases were personal needs of the grieving spouse met. Despite the relatively small sample of women, and a focus on the bereaved, this initial study encouraged future studies to be conducted on family needs.

In 1983, Molter and Leske developed the standardised questionnaire, the "Critical Care Family Needs Inventory" (CCFNI). The CCFNI enables families to rank the importance of each need from a list of 45 needs statements using a four-point response format (ranging from "not important" to "very important"). The 45 needs statements are divided into five dimensions:

- Assurance (7 items) e.g., "To feel there is hope"
- Information (8 items) e.g., "Consistent, realistic and timely information"
- Proximity (9 items) e.g., "Personal contact and to near the patient"

- Comfort (6 items) e.g., “Family members, personal comfort”
- Support (15 items) e.g., “Resources and support systems”

The reliability of this measure has been tested numerous times, and has been demonstrated as being acceptable by Cronbach’s alpha values ranging from 0.61 to 0.88 (Leske 1991, Macey and Bouman 1991, Neabel et al. 2000, Lee and Lau 2003, Auerbach et al. 2005). A Cronbach’s alpha co-efficient of between 0.61 and 0.88 is considered acceptable (Devellis 1991).

The CCFNI has been extensively used to gather data on family needs from both family members as well as healthcare providers. **Table 3** summarises a selection of studies on family needs from the perspective of the family (**Appendix II**). Five quantitative studies (Molter 1979, Lee and Lau 2003, Auerbach et al. 2005, Omari 2009, Alsharari et al. 2019), four qualitative studies (Coulter 1989, Bond et al. 2003, Fry and Warren 2007, Keenan and Joseph 2010), and two literature reviews (Verhaeghe et al. 2005, Al Mustair et al. 2013) were identified that explored family members’ perceptions of their needs. The published literature on family needs is predominantly replications of the work of Molter (1979), conducted and published largely in the years 2000–2010. All five quantitative studies used the CCFNI.

Previous quantitative studies using the same methodology, and two literature reviews, have consistently shown that family members rank the need for assurance and information as their greatest need, followed by proximity, comfort, and support, respectively (Molter 1979, Lee and Lau 2003, Auerbach et al. 2005, Verhaeghe et al. 2005, Omari 2009, Al Mustair et al. 2013, Alsharari et al. 2019). In particular, three of the top-ranked needs statements on the CCFNI relating to

the assurance dimension were: “to know specific facts related to the patient’s status”, “to be assured that the best care possible is being given to the patient”, and “to feel there is hope”. Within the information dimension, “having questions answered honestly” and to “know that the patient is being treated medically” were the most highly ranked statements on the CCFNI. These statements within the CCFNI underline the importance that families place on information and assurance needs. Delivering this level of assurance and information to families not only lays the groundwork for establishing their understanding of their relative’s wishes and values, but also provides reassurance for hope regarding their relative’s outcome (Maxwell et al. 2007).

Qualitative studies of family needs enabled family members to present their perspectives more explicitly. Bond et al. (2003) found that families wanted to be told the facts about their relative’s condition, even if it clashed with, or indeed compromised, their need for hope. Kennan and Joseph (2010) expressed that families display an intense need for information and emotional support, and the opportunity to participate in the physical care of their loved one.

Family members actively seek to access information and create an alliance with ICU staff, as both were deemed to positively impact on their ability to cope with the worrying and difficult situation they were facing (Bond et al. 2003, Fry and Warren 2007, Keenan and Joseph 2010). Those family members who were confident and who trust in the ICU staff’s ability to care for their relative felt more able to leave at night and take care of both themselves and other family members (Fry and Warren 2007). Conversely, those who perceived a lack of trust or engagement with healthcare staff describe difficulty in coping, lack of confidence,

hesitancy to ask questions, and dissatisfaction with the care provided (Fry and Warren 2007). Bond et al. (2003) also explained that the inclusion of family members by the ICU team not only increased their understanding of the gravity of their relative's condition, but this also helped prepare them for their potential caregiver's role on discharge from hospital.

Although there is consistency across studies in how the importance of family needs have been ranked, variations do occur (Auerbach et al. 2005, Young et al. 2005). These variations in rankings can be attributed to insufficient distinctions made between different types of illness. For example, scheduled admission to the ICU after successful surgery may be experienced differently to that of an unanticipated and emergency admission to ICU from a sudden cardiac event or road traffic accident (Mitchell and Courtney 2004, Auerbach et al. 2005, Young et al. 2005). This suggests the importance of accounting for the nature of the patient's admission into ICU and ensuring adequate sample sizes for subgroup analysis in all studies investigating family needs.

From the studies reviewed, the importance of family needs has been recognised by families in different populations and locations, and those with different cultural backgrounds. Age, gender, relationship to the patient, length of patient's stay in the ICU, and patient's diagnosis were not found to be correlated with family members' ranking of needs, but types of needs may vary depending on the source of the critical illness. These findings are not unexpected as, when a loved one is in a critically unwell condition, the primary concern of all family members will be on seeking information regarding their critical illness and to be assured that they are receiving the best and highest quality of care.

2.9.2: Healthcare staff's perceptions of family members' needs

Few studies have evaluated family needs from the perspective of the ICU medical and nursing team (see **Table 11, Appendix II**). Four single-centre quantitative studies (Leung et al. 2000, Bijjtebeir et al. 2001, Kinrade et al. 2010, Ozbayir et al. 2014), and one multicentre qualitative study, included only nursing staff (Hinkle et al. 2009). Three studies evaluated both medical and nursing staff's perspectives of family needs; two using quantitative methods (Bijjtebier et al. 2001, Hinkle and Fitzgerald 2011), and one a mixed-methods study (Takman and Severinsson 2006). Findings from quantitative studies using the CCFNI highlight that there was substantial similarity between the ratings of family needs by nurses and doctors. The two most important needs statements on the CCFNI ranked highest by both nurses and medical staff were "Information and assurance", specifically, the need statements, "to have questions answered honestly", "to be assured the best possible care is being given", and "to have explanations given that are understandable" (Leung et al. 2000, Bijjtebeir et al. 2001, Kinrade et al. 2010, Hinkle and Fitzgerald 2011).

In one study, nurses ranked proximity need statements on the CCFNI more highly than assurance or information need statements (Ozbayir et al. 2014). The need for families to be near their relative is a key priority in the current clinical practice recommendations for FCC and can be met through open visiting (Davidson et al. 2017). Increased visiting hours allows families the opportunity to remain emotionally close, directly participate in their care, and offer psychological support to their relative (Lam and Beaulieu 2004, Karlsson et al. 2011, Fumis et al. 2015). Spending time in the ICU environment with their relative has been found to help family members feel like they are "fitting in" and assists in their

understanding of the ICU culture (Lam and Beaulieu 2004). For some, spending this additional time in the ICU, the less intimidated they become with the technological and often noisy environment, and they are more confident in asking questions and engaging with ICU staff (Lam and Beaulieu 2004). Being in the vicinity and near to their family member also helps them adjust to the emotional distress produced by this unanticipated episode of critical illness (Verhaeghe et al. 2005, Pryzby 2005).

2.9.3: ICU staff's ability to meet family needs

Meeting the needs of ICU family members has been recognised and acknowledged in the literature as a priority (Verhaeghe et al. 2005, Al-Mustair et al. 2013). Despite, for the last 40 years, assurance and information needs being ranked as the highest needs and nurses and doctors being in an ideal position to meet these needs, they are not always met (Molter 1979, Verhaeghe et al. 2005, Al-Mustair et al. 2013).

Nurses who are in closest contact with the patient and their family are instrumental in coordinating the information that is exchanged between healthcare professionals and family members (Adams et al. 2015). Yet, they frequently undervalue their role in providing specific information about the daily care of their patient, the reason for particular interventions, and changes in the patient's condition, or they assume that the information needs of the family have already been met (Verhaeghe et al. 2005). There is substantial evidence that nurses believe they are educationally underprepared to deliver some types of information, or they are afraid of not being able to provide families with the level of detail and/or adequate answers they require (Soderstrom et al. 2003,

Zaforteza et al. 2005, Engström and Söderberg 2007, Stayt 2007). This leads nurses to distance themselves from the family, making the priority of developing collaborative partnerships much more challenging, as they feel excluded from discussions (Soderstrom et al. 2003, Zaforteza et al. 2005, Stayt 2007). Furthermore, nurses are frequently physically unable to meet family needs as they are trained to focus on the nursing needs of the patient, especially when patients are physiologically unstable (Chien et al. 2006).

Medical staff underestimate their role in meeting family needs. This is because, similar to nurses, they are trained to focus on patients rather than family needs (Molter 1979, Bijttebeir et al. 2001, Davidson 2009, Day et al. 2013). The initial focus of their care in the ICU is on establishing and maintaining the physiological stability of the patient, and, therefore, attending to the family may not actually be possible at times (Davidson 2009). The severity of illness may dictate that time available for communication is limited, and that the ability to engage in discussion is further compromised by the patient's clinical condition (Lee and Lau 2003).

Families appreciate honest, understandable, and timely information, provided by a limited number of healthcare staff and communicated to them once a day, especially regarding their relative's condition, prognosis and precise treatment plan (Heyland et al. 2002). In clinical practice, the reality is that effective family communication is dependent not only on when and who is providing the information, but also their confidence and skills in their communication abilities. Moreau et al. (2003) sought to compare the effectiveness of information delivered to family members of the critically ill by both junior and senior medical staff in a multicentre randomized trial across 11 French ICUs. There were no significant

differences found between the two groups with respect to comprehension of diagnosis, prognosis and treatment. Two satisfaction parameters did differ statistically between the two groups: additional time; and seeking additional doctors from senior colleagues. Family members reported that junior medical staff ended interviews too abruptly, they would have preferred additional information time, and that they had sought additional explanation from their more senior colleagues. This study suggests that families receive assurance through discussions with more experienced ICU staff delivering this information.

In order to completely satisfy informational needs, providing the correct level of information that families understand does seem to require emotional maturity, psychological sensitivity, and an awareness of the factors that influence communication (Curtis et al. 2001). Acquiring this insight and knowledge takes both time and experience; it is therefore best delivered in the ICU clinical area by senior staff or by junior staff being supervised by senior staff (Moreau et al. 2003).

Being in close proximity to their relative is ranked as an important need for families and, at times, by nurses, yet, this need was often left unmet and a notable source of anxiety and stress for both patients and their family members (Verhaeghe et al. 2005, Ozbayir et al. 2014, Al Mustair et al. 2013). Ten years ago, patients admitted to the ICU in the UK were only allowed visitors during certain periods of the day. For example, Hunter et al.'s (2010) study of 206 UK ICUs reported that 80% ($n=164$) operated with a restricted visiting policy. These restrictions at the time were contrary to evidence of the benefits associated with flexible visiting and were not supported by the ICU family-centred care principles

and clinical guidelines published by the Society of Critical Care Medicine (Lam and Beaulieu 2004, Davidson et al. 2007, Karlsson et al. 2011, Fumis et al. 2015).

Since Hunter et al.'s (2010) UK study, Scotland has introduced open and flexible visiting as part of a national person-centred approach to support improvements in families' experience across hospitals. This approach has been policy driven by the Scottish Government (2018), who stipulated that, by 2020, all NHS Boards will have implemented a flexible visiting policy (Department of Health 2018). The ICU in this study site has operated an open and flexible family visiting policy since 2013. However, many ICUs around the world, which may include the rest of the UK, continue to practise a restricted visiting policy, which has been reported by families to be negative and burdensome (Fumis et al. 2015).

2.9.4: Summary

The majority of family needs studies were single-centred. Studies were largely conducted outside of the UK; the only UK study was conducted over 20 years ago. Interestingly, this study also ranked family members' needs for information and assurance as a top priority (Coulter 1989). All of the reviewed studies had obtained data during the acute phase of critical illness (24 hours to 72 hours after admission to ICU). Family needs measured at or near the time of admission may differ from the family's needs after a prolonged period of admission. Furthermore, research with the CCFNI only is too restricted in scope, thus preventing additional aspects of family experiences in the ICU from emerging. The qualitative studies that have been conducted so far have provided a description of the experiences of family members and have enabled the process that family members go through to be more fully understood.

What is evident across all research studies and the two literature reviews is the need for assurance and information. These are deemed to be the greatest universal needs, followed by proximity, support, and comfort, irrespective of the family member's background or culture. Families express the need for information to be accurate and honest with regard to the condition of their relative, provided in an understandable manner, and at a pace to ensure comprehension, but without leaving room for unrealistic hope (Bond et al. 2003, Takman and Severinsson 2006, Fry and Warren 2007, Keenan and Joseph 2010). However, family needs in the ICU are not always fulfilled, as medical and nursing staff primarily focus on meeting the patient's physiological needs (Molter 1979, Bijttebeir et al. 2001, Verhaeghe et al. 2005, Davidson 2009, Day et al. 2013). In doing so, families may feel uninformed, dissatisfied and disenfranchised from clinical decision-making and the day-to-day care of their relative, which produces family distress (Wall et al. 2007, Stricker et al. 2009).

2.10: Family satisfaction with care in the ICU

In recent years, knowledge about family experiences during their ICU stay has resulted in directing healthcare staff to focus on including family members in the provision of intensive care (Heyland et al. 2002). In particular, the concept of quality of care beyond the medical dimension, as perceived by ICU family members, is a current focus of interest. Whilst measuring quality of care is complex, given the involvement of families within ICU, the assessment of family satisfaction is considered to be a key outcome in this domain (Wasser et al. 2001, Heyland et al. 2002, Wall et al. 2007).

Research studies on family satisfaction are predominantly conducted through self-assessment questionnaires and require family members to contribute a personal reflection based on their evaluation of the ICU experience (Van den Broek et al. 2015). No clear definition of family satisfaction has been agreed in the ICU literature, however, the most cited definition of the concept is provided by Rothen et al. (2010), who stated that family satisfaction “reflects the extent to which perceived needs and expectations of family members of critically ill patients are met by healthcare professionals (p. 624).

Globally, the most widely validated measure of family satisfaction within the ICU setting is the Family Satisfaction in the Intensive Care Unit questionnaire (FS-ICU) (Van den Broek et al. 2015). This tool describes satisfaction overall, and, in a further two sub-domains, satisfaction with care, and satisfaction with information/decision-making, used as surrogate markers of quality of care (Heyland and Tranmer 2001).

In contrast to family needs, studies on family satisfaction in the ICU setting are fewer in number and limited in scope (see **Table 12, Appendix II**). Eleven studies used the (FS-ICU) questionnaire, seven included the FS-ICU quantitative questionnaire only (Heyland et al. 2003, Hunziker et al. 2012, Gersaimou et al. 2013, Hwang et al. 2014, Frivold et al. 2016, Ferrando et al. 2019, Haave et al. 2021), and a further four included both the quantitative and the qualitative components of the FS-ICU (Hendrich et al. 2011, Schwarzkopf et al. 2013, Clark et al. 2016, Min et al. 2018). Two studies utilised the Critical Care Family Satisfaction Survey (CCFSS) (Karlsson et al. 2011, Eltaybani and Ahmed 2021), and, of these, one included a quantitative and qualitative analysis of this

questionnaire (Karlsson et al. 2011), and the other provided a quantitative analysis and semi-structured interviews (Eltaybani and Ahmed 2021). The final study implemented a family satisfaction questionnaire developed by the researchers (Sundararajan et al. 2012).

2.10.1: Family satisfaction and gaps in quality of care

A number of studies have highlighted that families of the critically ill are highly satisfied with the overall care that their relative and they themselves receive, especially with aspects of care regarding skill and competence of staff, and the respect given to their relative (Heyland et al. 2002, Hwang et al. 2007, Hendrich et al. 2011, Hunziker et al. 2012, Sundararajan et al. 2012, Schwarzkopf et al. 2013, Gerasimou et al. 2013, Clark et al. 2016, Frivold et al. 2016, Min et al. 2018, Ferrando et al. 2019, Haave et al. 2021). Conversely, Eltaybani and Ahmed (2021), using the CCFSS in a cohort of ICU family members in Egypt, was the only study to have found overall family satisfaction to be low. Lower satisfaction was directly related to low economic status, lack of resources, and the requirement to provide their relatives with medications and supplies not available in the ICU. Financial hardship in this study was a substantial source of family dissatisfaction.

Family satisfaction questionnaires have played an integral role in identifying quality of care gaps. For example, over the past 20 years, families have consistently reported poorer satisfaction with frequency of communication with medical staff, support with the decision-making process, and the ICU waiting area (Heyland et al. 2002, 2003, Hwang et al. 2007, Hendrich et al. 2011, Karlsson et al. 2011, Hunziker et al. 2012, Sundararajan et al. 2012, Gerasimou et al. 2013,

Clark et al. 2016, Frivold et al. 2016, Min et al. 2018, Ferrando et al. 2019, Eltaybani and Ahmed 2021, Haave et al. 2021).

Often, patients deteriorate rapidly before admission to ICU, leaving much less time for relatives to prepare for these events. Therefore, it is not surprising that adequate communication and good decision-making support are two key predictors of family satisfaction (Heyland et al. 2003). Families report greater satisfaction and support in their decision-making when clear and honest information was delivered to them in understandable language, enabling them to actively participate in the decision-making process (Heyland et al. 2002, 2003, Hunziker et al. 2012, Hwang et al. 2014). Heyland et al. (2002) found completeness of information was the single-most important factor accounting for the variability in overall satisfaction. Families who rated the completeness of information highly were much more likely to be completely satisfied with their ICU experience.

When asked to report on satisfaction with frequency of communication with ICU medical staff, family members in Canada (Heyland et al. 2002, Hendrich et al. 2011), the USA (Hwang et al. 2007, Clark et al. 2016), and Germany (Schwarzkopf et al. 2013), perceived lower satisfaction. For family satisfaction measured by means of the CCFSS, or tools developed by researchers, families documented they would have preferred medical staff to be more available for regular updates (Karlsson et al. 2011, Sundarariajan et al. 2012, Eltaybani and Ahmed 2021).

The structure of the FS-DM subscale, however, does not provide information on family satisfaction with the content of the conversation or access to information

from ICU staff. It is arguable whether these are more important in achieving a higher degree of satisfaction than frequency of communication alone. Family members' perceptions of a lack of information may be because they did not understand or absorb the information received. Karlsson et al. (2011) found that 50% of family members had not fully understood the information that had been provided to them. Azoulay et al. (2000), after surveying 26 family members of critically ill patients, found 30–50% of families were unable to comprehend diagnosis, prognosis or treatment. This was based on assessments of the families' comprehension of what the medical staff communicated during family meetings. Families who were interviewed displayed poor comprehension of diagnosis (20%), prognosis (43%), and treatment (40%), or a combination of these factors (54%). Factors associated with poor comprehension, influencing overall satisfaction, included age, language, nature of illness, employment status, relationship of the family member to the patient, and prognostic category. Overwhelming feelings of anxiety and uncertainty prevent them understanding even the most basic information, especially in the early period of their ICU journey (Johnson et al. 2019).

Receiving contradictory information from the ICU staff is another reason for family dissatisfaction. For example, Azoulay et al. (2001), in a prospective multicentre study, found that families who felt they had received contradictory information displayed 21.5% lower satisfaction scores than their counterparts and were less satisfied. Satisfaction improved when families were provided information in a frank, direct and empathetic way by the same ICU medical and nursing staff, that is, those who were well aware of the structure and balance of relationships within the family.

2.10.2: Differences in satisfaction between ICU survivors and ICU non-survivors

Families of ICU non-survivors, or those with high severity of illness, rate overall satisfaction higher than families of those who survive (Wall et al. 2007, Stricker et al. 2009, Frivold et al. 2016, Ferrando et al. 2019, Haave et al. 2021). There was also a tendency towards greater satisfaction with decision-making in patients who were approaching end of life in comparison to those who survived ICU (Stricker et al. 2009, Frivold et al. 2016). In the largest UK study, incorporating 20 ICUs, Ferrando et al. (2019) recorded that family members of ICU non-survivors had higher scores for overall satisfaction and satisfaction with decision-making than did ICU survivors. Whilst this may seem counterintuitive, it is in part because of an increasing focus on improving end-of-life care in the ICU, rather than the broader population of the critically ill, most of whom survive (Curtis and White 2008).

Families of patients with higher illness severity and those who are dying require more time provided by the ICU team, which inadvertently results in less attention being paid to more “routine” patients and their families (Schleyer and Curtis 2013). Wall et al. (2007) agree that the results do not indicate that families of those who die received better care, but indicate the extra effort that ICU staff make to meet family wishes as death approaches. Conversely, other researchers have found no correlation between the patient’s survival status and family satisfaction (Hunziker et al. 2012, Schwarzkopf et al. 2013). All family members, irrespective of illness severity or outcome, need to be fully integrated into the communication process (Cox et al. 2018).

2.10.3: Family experience in ICU

In contrast to satisfaction, exploring the experiences of family members within the ICU requires researchers to enquire about their actual ICU experience rather than being asked to rate their experience using general evaluation categories (poor, fair, good, very good, excellent). A common problem of assessing family satisfaction by questionnaire is the high number of extremely positive responses, also found in previous family satisfaction surveys (Heyland et al. 2002, Hwang et al. 2007, Hendrich et al. 2011, Hunziker et al. 2012, Sundararajan et al. 2012, Schwarzkopf et al. 2013, Gerasimou et al. 2013, Clark et al. 2016, Frivold et al. 2016, Min et al. 2018, Ferrando et al. 2019, Haave et al. 2021).

Few studies have reported qualitative analysis of responses to the open-ended questions in the FS-ICU to identify and describe themes to provide a fuller picture of family member experiences (Hendrich et al. 2011, Karlsson et al. 2011, Schwarzkopf et al. 2013, Clark et al. 2016, Min et al. 2018 (see **Table 12, Appendix II**)).

Hendrich et al. (2011) identified 6 themes which emerged as being central to family members' overall ICU experience: communication with medical staff, quality of medical care, quality of staff, compassion and respect, family waiting room, and patient rooms. The selection of themes was well-supported through rich description. Min et al. (2018) found the same six themes, but added an additional "others" theme. Positive comments were more common for: quality of the staff, overall quality of the medical care provided, and compassion and respect shown to the patient and family. Positive comments were less common for: communication with doctors, ICU waiting room, and visiting hours.

Comparable themes emerged from family comments in Schwarzkopf et al.'s (2013) study, where positive comments generally outnumbered negative comments, and the themes that received mixed positive and negative comments by at least 5% of respondents were: communication, compassion/respect for the family/patient, and the ICU waiting room. In contrast, Clark et al. (2016) identified that 50% of family members described the need for better communication, accurate and timely information, and improved waiting area facilities.

Exploring family experiences during semi-structured interviews, Eltanybani and Ahmed (2021) described four similar key themes: aspects of family care, aspects of patient care, organizational and administrative issues, and the ICU environment. Lack of regular communication with the ICU medical team, absence of a dedicated area for holding a family meeting, restrictive visiting hours, and the uncomfortable waiting area were expressed by most participants in negative terms.

The findings from the qualitative analyses provide insight that aids in interpreting the quantitative data. For example, where families are least satisfied with communication from medical staff, the frequency of negative comments received for communication with medical staff supports this (Hendrich et al. 2011, Karlsson et al. 2011, Schwarzkopf et al. 2013, Clark et al. 2016, Min et al. 2018, Eltaybani and Ahmed 2021). Moreover, the comments made by the family members in these studies portrays the emotions that were associated with this lack of communication and contribute to the psychological burden of the family members.

Family members talked about the waiting room in a negative context, providing a deeper insight into elements of their ICU experience that were particularly significant to them. The negative evaluations have been related to the size of the patient's room, cleanliness and appearance of the waiting room, and lack of privacy related to a shared room, especially when a family meeting is held (Hendrich et al. 2011, Schwarzkopf et al. 2013). Furthermore, when families are not in close proximity to their relatives, they spend the majority of their time alone in these waiting areas, where they also experience what is described as “the emotional hell of waiting”, which they find isolating, distressing and anxiety-provoking (Bournes and Mitchell 2002, Iverson et al. 2014).

Waiting room amenities and providing comfortable surroundings are therefore shown to be crucial in influencing not only family satisfaction and enhancing their experience but also the psychological response in families of the critically ill. Dietrick et al. (2005) published quality improvement project findings where recommendations to upgrade the ICU waiting room, based on family wishes and comments, were proposed. Families were consistent in their desire to have better access to food and beverages, a variety of comfortable seating, television and/or reading material, computer access, and a private area within the waiting room. This indicates that improving the ICU environment should be a high priority and deserves attention from the ICU teams.

2.10.4: Summary

Family satisfaction is a basic component of quality that has gained increasing interest as an outcome measure in healthcare and for the assessment of the quality of care in the ICU. Measuring family satisfaction is a significant factor for

quality improvement in the ICU because this offers valuable information regarding the efficacy of care delivered.

Family members are consistently highly satisfied overall and with the quality of care that their relative and they themselves receive. They are less satisfied with decision-making unless the patient is approaching end of life, frequency of communication with medical staff, the ICU waiting room, and restrictive visiting hours. Families report greater satisfaction with information needs being met when the information about their relative was provided regularly, using simple terminology, and creating realistic expectations, preferably delivered by the same medical and nursing staff.

Communication with families is, however, dependent on many factors, such as the clinician's communication skills, level of psychological distress, and cognitive capacity, which may lead to a reduced understanding of their relative's critical condition or recollection of the information provided, as well as social elements, which may influence the way in which information is understood. Failure to recognise these and to manage each family's own expectations from the beginning of their ICU journey might not only undermine but also introduce barriers to communication efforts with families.

The qualitative analyses in the reviewed studies evaluated the ICU experience directly through feedback from family members. Family members were able to express which aspects of their ICU experience affected their satisfaction, providing essential context often missing in quantitative data. The psychological impact related to the stay of their relative in the ICU is one of the burdens that family members experience the ICU.

Family satisfaction is a frequently measured quality of care indicator at the study site ICU. Therefore, the use of a family satisfaction survey was the preferred tool in this study. However, the three open-ended questions included in the tool will simultaneously provide the opportunity to explore in family experiences of their relative's care in more depth.

2.11: Factors impacting on family well-being and ability to cope

It was not until the early 1990s that investigators began to appreciate that family members in the ICU could potentially have clinically diagnosable psychological symptoms. Pérez-San Gregorio and colleagues (1992), using the clinical analysis questionnaire, evaluated 76 family members of ICU patients with traumatic head injuries. They found that more than 50% of family members reported symptoms of depression, hypochondria, suicidal depression, low-energy depression, and anxious depression. Although these investigators focussed on family members from a specific population of patients, they published one of the first studies to suggest that patients' relatives may have psychological symptoms that could be detrimental to their own physical and mental health.

In the last 10 years, there has been a significant increase in the number of studies focussed on the psychological changes undergone by the ICU family. These indicate that families are at high risk of developing psychological disorders such as anxiety, depression, posttraumatic stress disorder, and complicated grief (Davidson et al. 2012). Consequently, the task force of the Society of Critical Care Medicine (SCCM), when exploring family responses to critical illness, has proposed a new term for this cluster of complications: post-intensive care

syndrome-family (PICS-F) (Needham et al. 2012). PICS-F refers to the acute and the chronic psychological effects of critical illness on the family, which includes the symptoms they experience during the critical illness as well as those that occur following their relative's death or discharge from the ICU (Needham et al. 2012). Families must also deal with the unfamiliarity of the ICU environment, the treatment procedures and the uncertainties of their relative's outcome, which creates further distress (Needham et al. 2012, Wong et al. 2017). Anxiety and uncertainty were two key factors identified in the literature in relation to factors that had an impact on family psychological well-being and capacity to cope.

2.11.1: Anxiety

Anxiety is defined as a heightened state of uneasiness to a potential threat that is inconsistent with the expected events, and occurs when there is a mismatch between the next likely event and the actual event (Bay and Algase 1999). Clinical symptoms of anxiety consist of increasing tension, worry, fright, trembling, quivering voice, jitters, hypervigilance and repeated questioning of staff (Leske 1991, Bay and Algase 1999).

Twelve studies examined anxiety in family members of the critically ill (see **Table 13, Appendix II**). Two review articles were identified: one literature review, which focussed on the short- and long-term psychological impact of critical illness on ICU family members (Paul and Rattray 2008); and one systematic review, which documented the prevalence of their psychological disorders and evaluation of clinical interventions to reduce these (Johnson et al. 2019). Nine of the studies on anxiety adopted quantitative approaches (Pochard et al. 2001, 2005, Delva et al. 2002, Rodriguez and San Gregorio, 2005, Young et al. 2005,

Paparringopoulos et al. 2006, Day et al. 2013, McPeake et al. 2016, Bolosi et al. 2018), and one study, a qualitative approach (Iverson et al. 2014). Most studies were single-centred.

The presence of anxiety symptoms in family members of patients admitted to the ICU ranged from 40% to 73% (Pochard et al. 2001, 2005, Delva et al. 2002, Rodriguez and San Gregorio 2005, Young et al. 2005, Paparringopoulos et al. 2006, Day et al. 2013, McPeake et al. 2016, Bolosi et al. 2018). Risk factors associated with an increase in symptoms of anxiety included being female, a spouse, an unplanned ICU admission, lower educational status, poor sleep pattern, fatigue, lack of regular meetings with medical staff, and failing to meet family needs (Pochard et al. 2001, 2005, Delva et al. 2002, Paparringopolous et al. 2006, Day et al. 2013, McPeake et al. 2016, Bolosi et al. 2018, Johnson et al. 2019). Family members who were provided with more social support experienced lower anxiety after their relative was transferred from the ICU to a general ward (Mitchell and Courtney 2004). Paul and Rattray (2008) and Johnson et al.'s (2019) review articles reported that moderate to high levels of anxiety persist for months up to years after discharge from ICU, however, the number of family members experiencing these symptoms does decrease over time. Furthermore, regardless of the time that anxiety symptoms were assessed, family members had a higher incidence of these symptoms than the general population (Johnson et al. 2019).

Only one of the nine quantitative studies found the prevalence of anxiety in family members of patients who died in the ICU, compared with family members of ICU survivors. Both groups experienced high prevalence rates of anxiety; however,

the difference in prevalence between the two groups did not reach a level of significance (Pochard et al. 2005). Therefore, although a patient's death on the ICU is a significant risk factor for psychological symptoms, family members of patients who survive are also at a similar level of risk.

Using semi-structured interviews, Iverson et al. (2014) explored family members' challenges in making decisions around the care of their critically ill relative. Communication was a primary contributor in their decision-making anxiety. They described the strain of uncertain outcomes and decision-making without being provided with clear and consistent information from ICU team. This left family members feeling helpless and vulnerable. They expressed having difficulty processing information that was highly technical and difficult to understand.

Their role as surrogate decision-makers amplified their anxiety at an already challenging time, and they were afraid that they were making the "wrong" decision on behalf of their loved one. They conveyed that, at times, treatment options were presented using unfamiliar language and terminology so as to exclude them from the decision-making process. On the other hand, many spoke of the positive experiences they had in communicating with the ICU team, which helped them remain focussed. The qualities they believed that eased their anxiety and ability to cope was perceived transparency, inclusivity, availability to answer questions, clarity of information, patience, and responsiveness to their concerns.

2.11.2: Uncertainty

Five studies have explored the uncertainty that families face when a relative is admitted suddenly and unexpectedly to ICU and how this contributes to feelings

of anxiety and an inability to cope with the magnitude of the situation (Jamerson et al. 1996, Burr 1998, Johansson et al. 2005, Ågård and Harder, 2007, Wong et al. 2017) (see **Table 13, Appendix II**). Four of the studies were qualitative studies. One mixed method study employed the CCFNI questionnaire and semi-structured interviews (Burr 1998).

In 1988, Merle Mishel theorized that the lack of knowledge of the issues related to illness leads a person to experience a state of uncertainty. She described this in her theory of Uncertainty in Illness, a theory that can be applied to patients, families/caregivers and parents of children. She defined it as the:

inability to determine the meaning of illness-related events which occurs in situations where the decision maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes because sufficient cues are lacking.
(Mishel 1988, p. 225)

It has also been described in the context of vagueness, ambiguity, lack of information, unpredictability, inconsistency, unfamiliarity, and temporality (Webster 2002).

The anxiety experienced by family members is underpinned by their uncertainty because it is unclear whether their relative will survive or suffer permanent disability, as well as having the daily fear of complications arising (Johansson et al. 2005). Moreover, the ICU environment has proved to be a challenge, specifically because the highly specialised medical equipment and technology, with which the family members are not familiar, contributes to further anxiety and uncertainties (Ågård and Harder 2007, Wong et al. 2017).

Waiting for information is a commonly experienced theme that is closely associated with uncertainty (Ågård and Harder 2007, Wong et al. 2017). Providing information has been described as an “antidote” to the fear of uncertainty and helps families tolerate and understand the situational crises in which they find themselves (Lam and Beaulieu 2004). The need to seek out information on the patient’s condition and prognosis was a consistent theme in all studies (Jamerson et al. 1996, Burr 1998, Johansson et al. 2005, Ågård and Harder 2007, Wong et al. 2017).

Ågård and Harder (2007) found that, although relatives of the critically ill were clearly in turmoil, they found ways of coping. Family members seek cues from their relative’s bedside monitors, the environment (for example, observing the actions of nursing and medical staff) and “from listening to sounds and noticing surroundings in the ICU” (Ågård and Harder 2007, p. 174). They monitor for changes in their relative’s condition, comparing and contrasting it with information given by the ICU staff so as to make sense of and formulate their own diagnosis as part of their repertoire of coping mechanisms. Jamerson et al. (1996), in an early study using focus groups, also describe a similar process that relatives undertake, which appears to relate to the coping mechanisms they put in place. For example, hovering, searching for information, tracking and gathering resources, and seeking social support.

Families want to be by the bedside at all times to seek out the information they require, have the opportunity to be of some help, watch over their relative, and feel assured that everything was being done in the best possible way. Seeking the information needed and knowing what was happening around them was an

active and focussed strategy in their constant effort to manage the evolving situation (Ågård and Harder 2007). If information was shared, for example, about the equipment and technology, then family members felt comforted. If there was the perception that information was being withheld, then families became suspicious and mistrustful of staff and fearful about their relative's safety (Wong et al. 2017).

It is the "not knowing" that was described as the worst part of the families' entire ICU experience, leading to profound feelings of uncertainty, anxiety and distress until sufficient cues were given or obtained by medical and nursing staff (Burr 1998, Jamerson et al. 1996, Ågård and Harder 2007). However, a key issue reported by Ågård and Harder (2007) was that family-acquired cues were not always shared with nursing and medical staff. For family members in their study, the assessment was at times a "silent process", which Ågård and Harder (2007 p. 175) suggest led to misunderstandings. It could be argued that, if this process is silent, then this may account for the reported low levels of family comprehension regarding their relative's prognosis, diagnosis and treatment (Azoulay et al. 2000).

Large amounts of emotional energy are used during periods of waiting to gain access to their relative and obtaining information from staff. Families feel helpless and lacking in control when they do not receive adequate information, where feelings of anxiety and uncertainty persist until such information is provided (Lam and Beaulieu 2004, Wong et al. 2017). When ICU medical or nursing staff fails to provide information in a timely manner, a perception of being kept in the dark

influences the extent of their uncertainty and intensifies their anxieties (Wong et al. 2017).

High levels of anxiety and uncertainty result in family members overestimating or underestimating the risks and/or benefits of clinical treatments, which impair comprehension and decision-making capabilities (Azoulay et al. 2000, Pochard et al. 2001, Mitchell and Courtney 2004, Ågård and Harder 2007, Iverson et al. 2014). Anxiety, and dealing with the psychological stress of uncertainty, therefore, has important implications for family members who participate regularly in decisions regarding the care of their relative. Meeting informational and assurance needs by providing timely and accurate information, as well as preparing families for transitions in the delivery of care, may minimise the uncertainty and anxiety they experience (Azoulay et al. 2000, Mitchell and Courtney 2004).

2.12: Psychological interventions

Effective communication and developing a collaborative partnership between ICU staff and their family members is vital for family-centred care to be fully recognised (Azoulay et al. 2000, 2001). It is acknowledged that families with relatives in ICU do indeed require more communication than is currently provided (Azoulay et al. 2002). However, there has been limited research into interventions to improve communication between family members and ICU staff in an attempt to reduce their psychological symptoms.

Twelve studies investigated interventions to improve family needs, family satisfaction, anxiety, depression, and post-traumatic stress disorder (PTSD). These studies included seven randomised controlled trials (Azoulay et al. 2002,

Jones et al. 2004, Lautrette et al. 2007, Yousefi et al. 2012, Garrouste-Orgeas et al. 2016, White et al. 2018, Cox et al. 2018), and five quasi-experimental studies (Appleyard et al. 2000, Mitchell and Courtney 2004, Chien et al. 2006, Mitchell et al. 2009, Othman et al. 2016) (see **Table 14, Appendix II**). Two of the randomised controlled trials examined family satisfaction with care as the primary outcome (Azoulay et al. 2002, Yousefi et al. 2012), whilst five trials investigated symptoms of anxiety, depression and PTSD as outcomes (Jones et al. 2004, Lautrette et al. 2007, Garrouste-Orgeas et al. 2016, Cox et al. 2018, White et al. 2018). Two quasi-experimental studies investigated the effect of needs-based interventions on family satisfaction (Appleyard et al. 2000, Chien et al. 2006). A third study examined respect, collaboration and support (Mitchell et al. 2009), the fourth examined the effects of information booklets on family members' satisfaction with decision-making (Othman et al. 2016), and, finally, the fifth examined the effects of introducing a pre-transfer educational information booklet on anxiety and uncertainty (Mitchell and Courtney 2004).

2.12.1: Randomised controlled trials

A diverse range of interventions were used in these studies with the aim of meeting the communication needs of families, and improving satisfaction and psychological well-being. Azoulay et al. (2002) distributed a family information leaflet (FIL) to supplement standardised family meetings to assess whether it improved their understanding of diagnosis and proposed interventions. The FIL, delivered at first visit to the family member, improved comprehension of diagnosis, treatment and prognosis ($p < 0.0001$). Satisfaction with care did not significantly differ between the two groups. However, although not statistically significant, among family members with good comprehension, the FIL was

associated with significantly better satisfaction. Yousefi et al. (2012) examined whether family satisfaction improved by allocating families a dedicated ICU support nurse. The intervention was based on a “family needs inventory”, where the ICU nurse’s role was to provide accurate explanations and information to families about the patient and their critical illness. Information and explanations were given regarding the ICU environment, equipment and personnel, as well as treatment, diagnosis, and prognosis. Meetings with the medical staff and allied health professionals were also facilitated. Family satisfaction in the intervention group was significantly increased post-intervention.

Lautrette et al. (2007) introduced a structured information brochure along with proactive family meetings for family members of patients in ICU with high likelihood of mortality. They found that family members in the intervention group had significantly fewer symptoms of anxiety, depression, and PTSD after 90 days post-ICU discharge than did family members in the control group. Family members in the intervention group had meetings of longer duration (thirty minutes versus twenty minutes) and more talking time (fourteen minutes versus five minutes) compared to the control group. No pre-test data were collected, which limits the confidence in the use of the structured communication intervention for these families.

In a later study, Garrouste-Orgeas et al. (2016) compared routine family meetings led by an ICU clinician versus those held without the proactive participation of the ICU bedside nurse. The intervention and control groups were not significantly different regarding the prevalence of PTSD-related symptoms. Anxiety and depressive symptoms were found to be significantly lower at 3 months in the

intervention group. The presence of the nurse was appreciated by the family members, who stated they felt that the nurse improved their trust that teamwork in the ICU was effective, and that this helped them to communicate with the ICU staff.

Conversely, White et al. (2018) introduced a multicomponent family support intervention delivered by a professional ICU team. There were no significant differences between the intervention group and the control group in the family members' anxiety and depression scores at six months. However, the quality of communication, and patient and family-centredness of care improved, and length of ICU stay was reduced. The authors postulate that the intervention may not have helped because it was completed during their ICU stay.

Cox et al. (2018) conducted a multicentre randomised controlled trial of ICU survivors and their family members who were randomly assigned to either a telephone/web-based coping skills training (CST) intervention or a standardised educational program two weeks following their relative's discharge from hospital. The CST intervention did not improve symptoms of anxiety, depression, and PTSD at three or six months among either patients or family members compared with those in the standard education program group. Jones et al. (2004) also failed to show that the provision of general written information around recovery after ICU, delivered by nurses, reduced anxiety, depression and PTSD symptoms at eight weeks and six months after ICU discharge. Some relatives remained anxious and met criteria for PTSD.

2.12.2: Quasi-experimental trials

Quasi-experimental trials have focussed on meeting family needs and the effect of family members assisting with the provision of care to the patient and family satisfaction (Appleyard et al. 2000, Mitchell and Courtney 2004, Chien et al. 2006, Mitchell et al. 2009, Othman et al. 2016). Results from five quasi-experimental studies suggest better family satisfaction with care and decision-making and reduced emotional distress post-intervention, compared to the usual care group (Appleyard et al. 2000, Mitchell and Courtney 2004, Chien et al. 2006, Mitchell et al. 2009, Othman et al. 2016).

For example, Chien et al. (2006) found that performing needs-based training on the patient's family needs, particularly psychosocial needs, assessed on admission to ICU, decreased anxiety and increased their satisfaction. However, cultural differences may have had an impact on the results of this study, and further investigations are required with families from different socio-economic and cultural backgrounds. Furthermore, the intervention itself was labour-intensive, and it was difficult to identify which specific aspects of the educational programme were effective. Appleyard et al. (2000) reported greater family satisfaction regarding comfort needs following the introduction of a volunteer programme in the ICU, but no differences were found for the other CCFNI needs, including information, assurance, proximity, and support. Notably, the volunteers reported that the nurses became more communicative and more concerned about families' needs following the introduction of the intervention. Mitchell et al. (2009) reported that family members invited to assist nursing staff in providing direct care to their relatives (intervention group) significantly improved respect, collaboration, support and overall satisfaction scores compared to those family

members receiving usual care. This study, however, only included the relatives of long-term ICU patients with a length of stay greater than 11 days, thereby limiting the results to this group of family members.

Othman et al. (2016) introduced an information booklet delivered to families 24 hours after ICU admission and compared this to family members receiving “routine usual care”. Family satisfaction with care, communication and decision-making was significantly higher in the intervention groups compared to those who received usual care. No descriptions were given as to the content of the information booklet or of what the differences were to family members receiving “routine usual care”, making interpretation of the findings difficult.

Mitchell and Courtney (2004) investigated whether state anxiety and uncertainty reduced in family members being transferred from ICU with either a pre-transfer educational information booklet or ad hoc transfer methods. Providing structured printed information did significantly decrease anxiety scores (from 41.62 to 37.72) in the intervention group, but a similar statistically significant decrease was seen in the control group (from 41.24 to 37.11), thus, providing information did not specifically reduce just their anxiety. Uncertainty was significantly reduced for the intervention group, but not the control group. Family members’ level of uncertainty did remain in the moderate uncertainty range; nonetheless, it was encouraging that uncertainty was reduced for those family members who experienced the intervention

2.12.3: Summary

Combined targeted written and oral information, delivered frequently by nurses and ICU clinicians, and involving the family directly in their relative’s care can

create realistic expectations for family members. In doing so, this can significantly increase comprehension, family satisfaction and satisfaction with decision-making (Azoulay et al. 2002, Chien et al. 2006, Yousefi et al. 2012, Othman et al. 2016).

Families who are provided with good knowledge about their relative's clinical condition and treatment options, and who are contacted throughout the day, either by phone or by attending a family meeting, were more satisfied. The regular phone calls or meetings ensured that families received updated daily information, had an opportunity to have questions answered, and were provided with support when difficult decisions needed to be made. Additionally, families conveyed greater satisfaction with their needs being met if they received information about the ICU environment and equipment, either through leaflets or discussions with staff, and were involved in the care of the patient at the bedside (Appleyard et al. 2000, Chien et al. 2006, Othman et al. 2016).

In contrast, intervention studies developed with the specific aim of reducing ICU family members' distress, evaluated in both in-patient (multicomponent family support) and outpatient settings (coping skills training, ICU rehabilitation manual), have mainly demonstrated little effect on reducing anxiety, depression symptoms or PTSD (Jones et al. 2004, Cox et al. 2018, White et al. 2018). Levels of psychological distress in these intervention studies were lower than levels that have been observed by Lautrette et al. (2007), making it difficult to reduce the burden of symptoms further. Furthermore, whilst Garrouste-Orgeas et al. (2016) report a significant reduction in anxiety and depression, the prevalence of severe anxiety and depression symptoms did not differ significantly between the two

groups. This highlights the magnitude of the psychological distress that family members continue to experience after they leave the ICU.

2.13: Family conferences

Family conferences, which comprise structured family meetings with doctors, nurses and families, have been successfully introduced within the oncology setting and, as has already been shown by Lautrette et al. (2007), Yousefi et al. (2012) and Garrouste-Orgeas et al. (2016), can be appropriate for family members of the critically ill. Regular family meetings are an important forum for discussions regarding their family member's condition, prognosis, and care preferences, and for listening to the family's concerns, and decision-making about appropriate goals of treatment (Curtis and White 2008). They have also been shown to improve patient outcomes, as family meetings delivered within 72 hours of ICU admission have been associated with fewer days in ICU of patients who die and with increased satisfaction with information provided to them (Lilly et al. 2000, Mosenthal et al. 2006, Glavan et al. 2008). Most of the published studies on family conferences have focussed on patients with a high probability of dying, however, family conferences may also improve communication throughout the ICU stay of patients who survive.

Gay et al. (2009) identified a number of barriers for successful family meetings, such as time, scheduling, conducting, multiple caregivers and lack of family goals. Strategies for improvement were also suggested, such as maximising the ICU team's time and using printed informational aids, and included a family meeting checklist and goals sheet. They proposed a multidisciplinary approach to facilitate the meetings, as ICU nurses develop the closest relationships with

both the patient and their family. Nursing staff are also present at the bedside for the majority of medical staff consultations, ensuring consistency of information.

Nelson et al. (2009) developed and published a new toolkit of three specific tools for implementation of family meetings (**Appendix IV**). The family meeting toolkit consists of: 1) a planner, 2) a family meeting guide, and 3) a medical documentation template. The planner tool sets out an initial sequence of activities, commencing when the patient is admitted to ICU, and is a means to standardise the implementation and documentation of family meetings (Nelson et al. 2009). This planner was developed from quality improvement work undertaken by Nelson and Colleagues in (2006) as part of a Care and Communication Bundle.

The family meeting guide is a visual aid, prompting family members to reflect on their current knowledge, record questions they may have, and document areas of concern in preparation for the meeting. These strategies encourage family participation in the meeting, inviting families to share, in their own words, what they understand about their family member's condition, what their concerns are, asking them to restate what they have heard during the meeting, and posing possible questions that families may be considering. Azoulay et al. (2016) suggest that family meetings should open with the question, "What is your understanding of what the clinical team expects to happen?" or "What has the team told you about what to expect?" If their answer differs from that of the medical and nursing staff, then this is the best place to start to identify the source of the discordance.

The family meeting documentation template provides a structured platform for documenting the communication between the family members and ICU healthcare team in the medical records. It also includes a check box for key topics to be discussed, such as prognosis, treatment goals and expectations, according to a defined sequence, and confirms the understanding of the family members attending the meeting (further information on the toolkit is provided in **Chapter 4**).

To date there are no known published studies investigating whether the structure of this communication intervention, which enables the conduct of family meetings in a uniform and timely manner by covering key points, improves psychological distress and family satisfaction in family members of patients who survive ICU.

2.14: Summary of the literature review

Admission of a relative to ICU is an unanticipated event and is designed for supporting individuals in a critical clinical state with the potential for high mortality. Critically ill patients are often unable to be involved in their plan of care, or to voice their needs, shifting the responsibility to the family. Family-centred care aims to recognise the needs of these family members and support them during critical illness. For family-centred care to be practised effectively in the ICU, clinical guidelines advocate consideration of the family in the care planning, actively involving them in their care, treatment plans and decision-making. ICU staff are therefore increasingly approaching the relative as an integral part of the family unit and subsequently expanding the care provided from the patient to the family members themselves.

This literature review identified a number of key issues, presented under four main headings. The needs of family members of ICU patients have been studied extensively since the seminal work carried out by Molter (1979) and the subsequent development of the Critical Care Family Needs Inventory (CCFNI). Both quantitative and qualitative studies of family needs consistently identify the need for information and assurance as their greatest and universal needs. Families want accurate and comprehensible information that leaves room for hope.

The desire for information was a common theme among ICU families, regardless of whether their relative survived or died. Furthermore, waiting for sufficient information was closely associated with uncertainty and intense anxiety. However, family needs are not always met, as ICU medical and nursing staff can underestimate their needs, and the level of importance that families attribute to these needs, resulting in dissatisfaction.

Families are highly satisfied overall with a large portion of their ICU journey, but there is reduced satisfaction with the quantity of communication, their involvement and support in decision-making, and the ICU waiting areas. The studies reviewed here identified that effectiveness of communication is assessed on two basic criteria: that of comprehension and satisfaction. Because of reduced cognitive capacity and psychological distress, families frequently fail to understand information, especially regarding diagnosis and prognosis. The ICU medical and nursing teams play an important role in providing clear and comprehensive information and in creating realistic expectations for family members in the ICU.

ICU family members need more time to develop cognitive understanding and acceptance of their relative's critical condition. There is some evidence that family interventions that are based on the provision of delivering appropriate written and oral information in ICU can improve understanding and expectations, effectively alleviate psychological symptoms, reduce uncertainty, and improve family satisfaction. Providing information in a variety of ways, ensuring that family members understand the nature of their relative's condition, treatment risk and benefits, has been shown to assist family members to cope with their situation.

Nelson et al. (2009) developed the family meeting toolkit, which aims to promote more timely and structured family communication within the ICU. However, no published studies have explored the feasibility and effectiveness of this approach. Therefore, the aim of the study was to evaluate the effects of delivering a structured communication strategy on anxiety, levels of uncertainty in illness, satisfaction with care and decision-making in families of critically ill patients in the ICU setting.

2.15: Limitations of the literature review

Only English-language articles were considered for inclusion in this literature review. As such, this review misses potentially relevant articles written in other languages. Most of the studies in this review involved female family members of the critically ill. The majority of studies were undertaken in the USA or Europe and obtained data from family members within 24–72 hours of admission to the ICU. This could affect the validity of the data because family members experience intense emotions and stress during and after this timeframe.

Although experimental studies were identified, there were some methodological weaknesses. Most studies were descriptive, non-experimental, single-centre studies with small sample sizes. As such, their findings may not be generalisable. There was an absence of theory to frame or guide the intervention, and each study identified limitations within their study design and outcome measures. Differences in study design and population, and in the number of samples and methods of intervention, make it difficult to compare the results. Several of the studies measured the effect of the interventions in reducing the family members' anxiety, however, it is difficult to ascertain whether the reduction in anxiety is because of the intervention itself or a predisposition to anxiety. Moreover, there is an identified lack of research into family members' levels of uncertainty and interventions to reduce its effects in the ICU setting.

CHAPTER 3: METHODOLOGICAL FRAMEWORK

3.1: Introduction

This chapter will describe and discuss the methodology adopted to meet the study aims, taking into consideration the clinical context and information obtained in the literature. The study design and setting will be considered first, followed by sampling and recruitment methods. Data handling and statistical analysis will then be discussed. The relevant ethical considerations and potential risks are examined, prior to presenting **Chapter 4**, where the process of modification and testing of the intervention will be outlined.

3.2: Aim

The aim of the study was to evaluate the effects of delivering a structured communication strategy on anxiety (state and trait), levels of uncertainty, and satisfaction overall with care and decision-making in families of critically ill patients in the ICU setting.

3.3: Research questions

Two research questions were identified to address this aim:

- In family members of ICU patients, how did the control group and intervention group state and trait anxiety, uncertainty in illness, and satisfaction overall with care and information/decision-making, change from the relative's admission to ICU to discharge from ICU?
- What effect did the introduction of the intervention (i.e., communication strategy) have over time on the intervention group compared to control group ICU family members' state and trait anxiety, uncertainty in illness,

and satisfaction overall with care and information/decision-making (time x group effect)?

3.4: Selecting the research design

The Department of Health's research strategy identified the need to ensure that healthcare practice, service organisation and delivery are underpinned by a sound evidence base (Department of Health 2006). To this end, research, service evaluation or clinical audit can be used to develop new knowledge, test new interventions or examine service organisation and care delivery (Gerrish and Mawson 2005). When deciding whether a project is research, audit or service evaluation, it is necessary to be guided by the underlying purpose of the project and by the questions to be answered. **Table 3** describes the key points to be able to discriminate between these three types of investigations (National Patient Safety Agency 2008).

Research, clinical audit and service evaluation have in common the need to employ systematic and rigorous methods to address clearly defined objectives (Gerrish et al. 2007). A key difference is that research attempts to derive new knowledge that is generalisable to other populations, whilst clinical audit and service evaluations are specifically concerned with generating new knowledge to inform local decision-making (National Patient Safety Agency 2008).

Table 3: Key differences between Research, Service Evaluation and Clinical Audit (National Patient Safety Agency 2008)

	Research	Service Evaluation	Audit
Aims	To derive new knowledge which is potentially generalisable or transferable.	To judge a service's effectiveness/efficiency through assessment of its aims, activities, outcomes and costs.	To improve the quality of local patient care and clinical outcomes through review of practice against evidence-based standards, and the implementation of change where subsequently indicated.
Treatments	May involve a completely new treatment.	Will never involve a completely new treatment.	Will never involve a completely new treatment.
Methodology	Addresses clearly defined questions /hypotheses using systematic and rigorous processes. Designed so that it can be replicated and results can be generalised to other groups.	Address specific questions about the service concerned. Results are specific and local.	Addresses clearly defined audit questions using a robust methodology, usually asking whether a specific standard has been met. Results are specific and local.
Randomisation	May involve allocating patients randomly to different treatment groups.	Never involves allocating patients randomly to different treatment groups.	Never involves allocating patients randomly to different treatment groups.
Ethical Approval	Ethical approval is required.	Most ethics committees exclude service evaluations.	Most ethics committees specifically exclude audit studies.

Within healthcare research, two broad research paradigms exist: the positivist paradigm and the naturalistic paradigm. Both have strong implications on the

choice of study method employed (Polit and Beck 2017). Quantitative research has its origins in positivism, which maintains that, in the world, there is an objective reality that can be observed and quantified in some way (Robson and McCartan 2016). The emphasis is on facts and the causes of behaviour, information is generated in the form of numbers that can be quantified and summarised, and a mathematical process is the norm for analysing the numeric data, where the final result is expressed in statistical terminologies (Robson and McCartan 2016). In contrast, qualitative research has its origins in the naturalistic paradigm, where the emphasis is on understanding people's feelings, thoughts, ways of understanding the world, or ways of communicating with others (Robson and McCartan 2016). Understanding the human experience as it is lived, usually through subjective qualitative materials, is a major limitation, as the level of subjectivity within this paradigm lacks reliability and validity (Polit and Beck 2017).

This study employed primarily a quantitative approach, based on the purpose of the research questions and the topic, although there was the opportunity for participants to comment in response to the three free-text questions introduced within the family satisfaction questionnaire. The design was experimental in the form of a quasi-experimental study using a pre- and post-test non-equivalent control group. In a pre-test – post-test design, with a non-equivalent control group, the experimental and control groups are measured at pre-test and post-test, but only the experimental group receives the intervention between the tests (Robson and McCartan 2016).

Although randomised controlled trials are often viewed as the gold standard for many types of research, there are times when the conditions of this type of design cannot be met, and a quasi-experimental design is the preferred alternative (Creswell and Creswell 2018). The quasi-experimental design, also called a “controlled trial without randomisation”, is frequently used in healthcare research and was chosen because it provides an experimental setting to determine whether the intervention (communication strategy) was effective where randomisation was not possible (Polit and Beck 2017). As the family members are not randomised in a quasi-experimental design, there is no equivalence between groups, hence why they are called “non-equivalent groups” (Krishnan 2019). This design was considered to be more feasible and practical, and deemed less time-consuming than a randomised controlled trial, to carry out within the clinical area of ICU (Creswell and Creswell 2018).

Further justification for the study design also comes from the comprehensive guidance developed by Handley et al. (2018), who advocate that “the strengths of pre-test–post-test designs are based mainly in their simplicity, such that data recollected is usually only at a few points” (p. 10). Data were gathered for the intervention and control groups at two time points – within 48 hours of the patient’s admission to ICU, and just prior to ICU discharge. Collecting data prior to and following the intervention aided the me in attributing the results post-intervention to the introduction of the intervention (Handley et al. 2018).

3.4.1: Control arm

The control arm of the study involved existing family informational support already operational in the study site, the ICU. There was variability in the

conducting of the meetings and in the documentation of their content following the family meetings that were held. They were based on medical staff's individual methods, family requests and the patient's clinical condition.

3.4.2: Intervention arm

The intervention arm consisted of three tools to aid with the organisation of a family meeting, which made up the family meeting toolkit developed initially by Nelson et al. (2009) (**Appendix IV**). These three tools, used by families prior to, during and post-family meeting, aimed to ensure the completion of critical steps that concluded in a structured family meeting (Nelson et al. 2009). The process of developing and adapting the family meeting toolkit is described in detail in **Chapter 4**.

3.4.3: Study setting

The study site refers to the overall location where the research, clinical audit or service evaluation is being undertaken (Polit and Beck 2017). The site selected must be able to fulfil the researcher's study aims and objectives, and access must be authorised by the relevant sites during the planning phase (Polit and Beck 2017).

The research study was conducted in a 19-bed ICU of a District General Hospital in Central Scotland. The ICU has a varied case mix of elective surgery patients and emergency admissions in general medicine, general surgery and cardiology. The total number of admissions during the study period, between July 2016 to February 2018, was 1918; of these, 228 patients died. The average length of stay of patients in ICU who were then discharged to the ward was 4.9 days.

3.5: Sampling strategy

The ideal sample would include the entire population; this would allow generalisations to be made about the results to the population as a whole, but time, money and resources prohibit this (Polit and Beck 2017). Therefore, a subset of participants, representative of a given population, must be selected. This is known as sampling (Polit and Beck 2017).

The aim of the sampling strategy was to recruit as representative a sample of participants as possible. Convenience sampling is the most common form of sampling, where participants are chosen because of their convenient accessibility to the researcher (Polit and Beck 2017). The convenience sampling method was used to recruit the most readily available participants for the study (Polit and Beck 2017). The recruitment of participants is entirely voluntary. Selection bias is an experimental error that occurs when the participants are not representative of the target population and is therefore a potential issue and a threat to the internal validity of the study (Polit and Beck 2017). This can make it difficult to confidently attribute any noted differences as a result of the intervention, rather than uncontrolled extraneous variables (Polit and Beck 2017). Selection bias from this type of sampling is recognised; however, I aimed to reduce bias by including all the accessible population of family members of patients who met the specified criteria.

The population consisted of family members of critically ill patients in one ICU of a District General Hospital. A convenience sample of 52 family members, who met the inclusion criteria set out below, were invited to participate in the study. Only one family member per patient was permitted to participate. A family

member for this study was defined as any person visiting the patient who was related by birth or marriage. Members of the immediate family included spouses, parents, brothers, sisters, sons and/or daughters. The family members were recruited from July 2016 to February 2018.

3.5.1: Inclusion criteria

The inclusion criteria for the study were:

- The spouse or first-degree family member of a mechanically ventilated critically ill adult
- Family member of a patient with no expectation of extubation or discharge from the ICU within 48 hours of admission
- Male and female family member, aged 18 years of age or over
- Available to participate in a family meeting
- Able to understand, read and write English
- Family member of a patient with a first admission to ICU
- Family member who was able to provide consent

3.5.2: Exclusion criteria

- Family member of a critically ill adult admitted to ICU for palliative care or patients with a previous ICU admission
- Family member of a ventilated patient not documented as next-of-kin
- Unable to complete the questionnaires because of language, cognition or cultural barriers
- Family member of a patient detained at Her Majesty's pleasure
- Family member of a patient repatriated to the study site ICU outside of the UK

- Family member unable to provide consent

3.6: Recruitment process

An experienced ICU research nurse was responsible for recruitment and data collection during the study period. Throughout the duration of this study, I had no clinical contact with the families who participated in the study during the data collection period. The research nurse was provided with an explanation of the purpose and procedures of the study, as outlined in the research nurse protocol in **Appendix V**.

3.6.1: Screening

The research nurse screened the patient's family members who were eligible for inclusion by consulting with the nurse-in-charge on each weekday during the study period. A screening and recruitment log was completed daily by the research nurse. All patients whose family member was considered suitable for the study and subsequently included or excluded from the recruitment process were documented on the screening and recruitment log (**Appendix VI**).

A total of 458 patients were assessed for study eligibility by the research nurse; of these, 383 were excluded at initial screening (**Figure 2**).

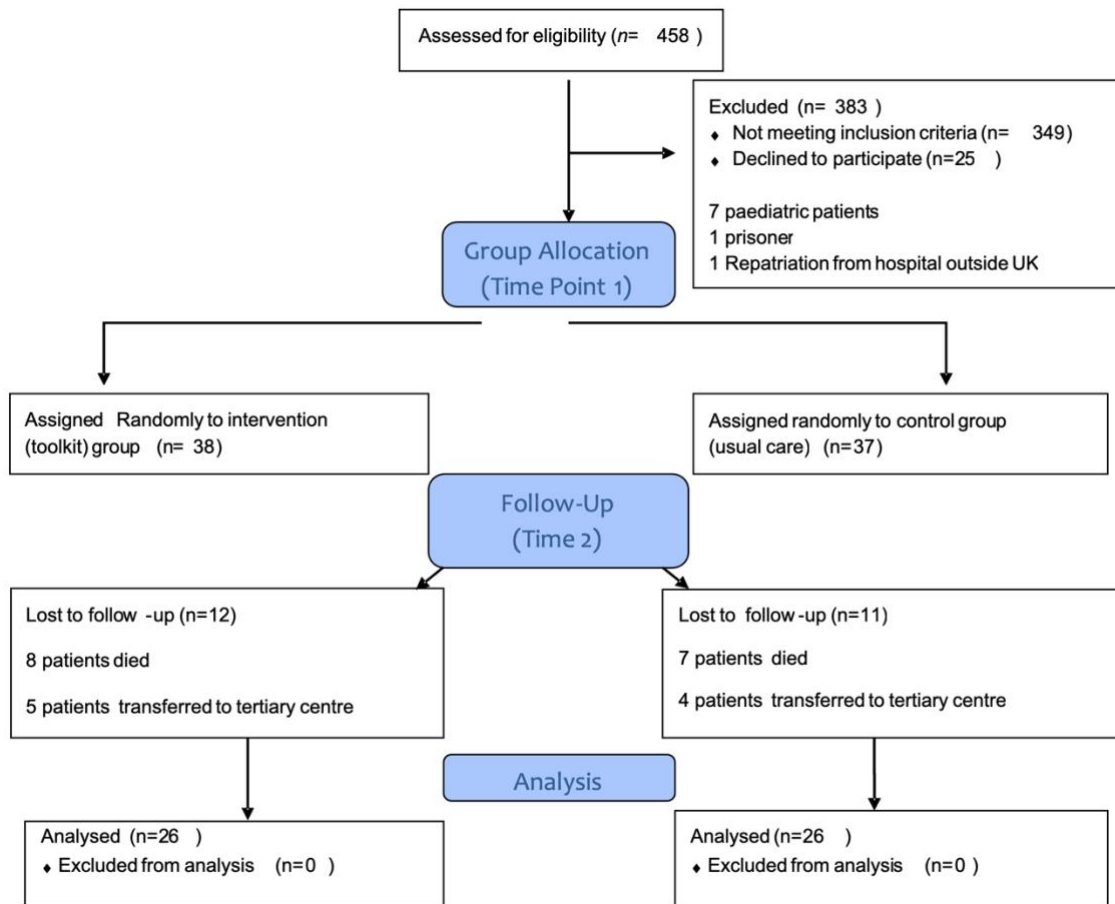


Figure 2: The CONSORT Diagram

3.7 Data collection

3.7.1: Variables

The dependent (outcome) variables include factors potentially influencing family members:

- 1) Levels of state and trait Anxiety
- 2) Levels of Uncertainty in Illness
- 3) Degree of family satisfaction overall, and with care and information/ decision-making

3.7.2: Socio-demographics

All family members were asked to complete a socio-demographic data sheet, which was attached to the FS-ICU questionnaire (**Appendix VII**). This included:

- 1) The family member's age,
- 2) Gender of family member
- 4) Relationship to the patient
- 5) Living arrangements with patient
- 6) Frequency of visits to the patient

3.7.3: Clinical data

Following a review of the literature (**Chapter 2**), only one published quantitative study was identified on uncertainty in illness in ICU family members (Mitchell and Courtney 2004). In addition to the patient variables measured in the study by Mitchell and Courtney (2004), this study also collected the following socio-demographic data for each patient to allow for comparison of study results and findings (**Appendix VIII**):

- 1) Patient's length of stay in ICU (LOS)
- 2) Patient's risk of morbidity (APACHE III) score
- 3) Patient's age
- 4) Reason for ICU admission
- 5) Expected or unexpected nature of the admission

3.7.4: APACHE III

The Acute Physiology, Age and Chronic Health Evaluation (APACHE) score is used to predict the hospital mortality risk for critically ill patients within 78 major medical and surgical risk categories (Knaus et al. 1981). The first APACHE score

was presented by Knaus et al. in (1981). The most recent APACHE III score (0–299) attributes a score to the patient’s age, severity and type of disease, and co-morbidities applied within the first twenty-four hours for all admissions to ICU (Knaus et al. 1991). Higher scores correspond with greater severity of illness and risk of death (Knaus et al. 1991).

Each patient’s length of stay (LOS), APACHE III score and reason for ICU admission were obtained by the research nurse from the ICU Electronic database, “Ward Watcher”. This database is used in all ICUs throughout Scotland, and contains details of each patient admitted to an ICU. Each ICU patient admitted onto Ward Watcher is allocated a unique five-digit key number, where patient clinical information is obtainable by healthcare workers. This key number was documented on the family socio-demographic sheet attached to the FS-ICU (**Appendix VII**) and the patient’s socio-demographic sheet (**Appendix VIII**) as a means of identifying patient/family questionnaire and clinical data.

3.8: Psychometric assessments

3.8.1: Self-report questionnaires

A self-report questionnaire refers to a structured series of written questions, which usually generate written responses, and is a common method used in service evaluations and clinical audits (Barker et al. 2015). The main advantages and disadvantages of questionnaire designs as a data collection tool are highlighted in **Table 4**.

Table 4: The main advantages and disadvantages of self-report questionnaires, reproduced from Barker, Pistrang and Elliot (2002)

Advantages	Disadvantages
Potential wider coverage of study population	Potential for low response rates
Low cost	Appropriate for less complex topics
Standardised	Difficult to construct
Allow respondents to fill them out privately	Risk of misinterpretation of the question
Less susceptible to social desirability bias (the tendency to answer questions in a socially acceptable way)	

A new questionnaire will require validity and reliability testing to establish that it measures what it is intended to measure and that it does this reliably (Barker et al. 2015). It is advised that investigators try to utilise existing questionnaires which have been shown to be both reliable and valid. This also allows study findings to be compared and contrasted (Barker et al. 2015).

Three validated self-report questionnaires were chosen for this study: 1) the State Trait Anxiety Inventory (STAI) (Spielberger et al. 1983), 2) the Parents' Perception of Uncertainty of Illness – family member form (PPUS-FM) (Mishel 1983), and 3) the Family Satisfaction with Care (FS-ICU) questionnaire (Heyland and Tranmer 2001) were completed by each family member at 2 time-points. Time-point 1 (TP1) was defined as baseline (within 48 hours of ICU admission), and Time-point 2 (TP2), just prior to discharge from ICU (**Appendix IX**).

3.8.2: State Trait Anxiety Inventory (STAI)

To measure level of anxiety, Spielberger's State-Trait Anxiety Inventory (STAI) questionnaire was used. The tool comprises separate self-report scales for measuring two concepts: state anxiety, and trait anxiety. This validated tool differentiates between the temporary conditions of anxiety (State) and a long-standing anxious quality (Trait). Trait anxiety refers to the innate tendency to feelings of anxiety and consists of feelings of apprehension, tension, and increased activity of the autonomic nervous system (Spielberger et al. 1983). Therefore, trait anxiety is relatively stable over time and considered to be an important feature of anxiety disorders (Kennedy et al. 2001). On the other hand, state anxiety refers to the temporary feelings of anxiety perceived by the person in a particular situation; if the individual perceives the situation to be threatening, levels of state anxiety are high.

For the purpose of this study, both state and trait anxiety scores were collected from both groups of family members at the two time-points and were used in the analysis. Comparisons of both state and trait anxiety were made, because people who are high in trait anxiety tend to perceive situations as being more threatening than people who have lower trait anxiety scores, and those with higher trait anxiety scores also tend to have higher state anxiety scores (Spielberger 1972). Moreover, trait anxiety has been shown to be able to predict panic attack, mental and physical health symptoms, and sleep difficulties (Weeks et al. 2019).

The STAI instrument has a total of 40 questions: 20 assessing state anxiety (STAI-S) and how a person currently feels, and 20 assessing trait anxiety (STAI-T) asking how a person generally feels. Each question is scored on a four-point

Likert scale with responses going from one (not at all) to four (very much so). The range of possible scores varies from a minimum of 20 to a maximum of 80 and the lowest total STAI score is 20, on both the STAI-S and STAI-T subscales. STAI scores are commonly classified as no or low anxiety (20–37), moderate anxiety (38–44), and high anxiety (45–80) (Spielberger et al. 1983). The measure requires approximately ten minutes to complete (Spielberger et al. 1983).

The instrument has undergone extensive psychometric testing and has been found to be a valid and reliable tool to measure anxiety (Spielberger et al. 1983). It has good internal consistency, with alpha coefficients ranging from 0.85 – 0.95; test–retest reliability with co-efficients ranging from 0.65 – 0.75, and discriminates psychiatric patients from healthy controls, making it ideal for examining changes in anxiety over time (Spielberger et al. 1983, Spielberger and Reheiser 2009).

The STAI has been used in a number of studies, including ICU, and in more than 60 languages, and is thus suggested as an appropriate instrument for this study (Spielberger et al. 1983, Delva et al. 2002, Mitchell and Courtney 2004, Paparrigopoulos et al. 2006, Chien et al. 2008). In an early study, Miller et al. (1995) compared three anxiety assessment measures in patients in the UK prior to elective surgery, the hospital anxiety and depression scale (HADS), a 100-mm visual analogue scale (VAS), and the STAI. They concluded that the scales were equivalent in their assessment of anxiety before surgery.

In this study, the Cronbach's alpha co-efficient for the STAI (total scale) was 0.881; for the State anxiety subscale it was 0.847; and for the Trait anxiety

subscale scale, 0.780. A Cronbach's alpha co-efficient of between 0.70 and 0.90 was considered acceptable (Devellis 1991).

3.8.3: Parents' Perception of Uncertainty in Illness Scale–Family Member Form (PPUS-FM)

The Parents' Perception of Uncertainty in Illness Scale (PPUS-FM) family member form is a self-report scale designed to measure the cognitive level of uncertainty in family members whose relative is unwell (Mishel 1983). The PPUS-FM was adapted from the Mishel Uncertainty in Illness Scale (MUIS), which measures "uncertainty of illness" in adult hospitalised patients to include families' responses to a relative's illness (Mishel 1981). The scale has 31 items rated on a five-point Likert scale, ranging from strongly agree (5) to strongly disagree (1). The total score is calculated by adding up the respondent's scores. There are 11 uncertainty absent items, for example, "The purpose of each treatment for any family member is clear to me", which are reverse-scored, and responses for five were changed to one, four to two, and so on. Total scores range from 31 – 155, and higher scores indicate higher levels of uncertainty experienced by a family member (Mishel 1983). According to Mishel (1983), a low illness uncertainty score is that below 59 points, medium is from 59 to 87 points, and high, that above 87 points. The questionnaire takes approximately ten minutes to complete (Mishel 1983).

Four factors are measured by the PPUS-FM scale: 1) Ambiguity (thirteen items), 2) Complexity (nine items), 3) Inconsistency (five items), and 4) Unpredictability (four items) (Mishel 1997). Ambiguity relates to the perception by the individual that cues given to them about the illness are obscure or unclear. Complexity is what information is known, the system of care and relationship with the

healthcare providers. Inconsistency refers to a disparity of information given to the individual concerning aspects of the illness. Finally, unpredictability is related to the individual's prognosis, quality of life, and ability to function (Mishel 1997).

The internal consistency reliability of the PPUS-FM was tested originally by Mishel (1983), who reported a Cronbach's alpha of 0.90 in a sample of 272 parents of hospitalised children. The subscales were all positively correlated with the total PPUS scale ($r=0.89, 0.80, 0.65, \text{ and } 0.50$, respectively) (Mishel 1983). The PPUS-FM has been administered among caregivers of patients with dementia, various cancers, or a medical illness (Mishel 1997, Harkness et al. 2013). Recently, Mitchell and Courtney (2004) used the PPUS-FM to investigate uncertainty in the ICU setting for the first time, where it was found that medium levels of uncertainty were reported by family members prior to and following transfer out of ICU (Mitchell and Courtney 2004).

Mishel (1997) advocates that, when using the PPUS-FM, a four-factor combined score should be used, as the reliability co-efficient for one factor is generally low. In this study, the Cronbach's alpha co-efficient was 0.84 for the total score, which is considered very good (DeVellis 1991).

3.8.4: Family Satisfaction Scale (FS-ICU)

The Family Satisfaction-ICU (FS-ICU) scale was developed by Heyland and Tranmer (2001) to assess family satisfaction. The scale has 24 items and describes satisfaction overall, and in two domains: *satisfaction with care*, and *satisfaction with decision-making*. Satisfaction with ICU care (FS-Care) has 14 items, and satisfaction with decision-making (FS-DM), 10 items (six information/ four decision-making). The FS-Care subscale includes questions regarding

nurses' communication skills as well as the care of both patient and their family member. The FS-DM subscale asks questions around the quality and frequency of the information provided and the involvement of families in the decision-making process. All items are rated on a five-point Likert scale, from excellent (0) to poor (5), except for one item, which uses a dichotomous scale (Question 10 on the decision-making scale).

As described by Wall et al. (2007), family satisfaction scores range from 0 – 100, (0=poor, 25=fair, 50=good, 75=very good, 100=excellent). Scores are calculated by averaging each available item, with higher scores indicating increased satisfaction overall, and with either care or decision-making. In addition, three free-text questions were included regarding the strengths and weaknesses of the Intensive care unit, based on the family members' experiences.

- 1) Do you have any recommendations on how care on ICU could be improved?
- 2) Do you want to mention something we did well?
- 3) Do you have any further comments or recommendations that could be helpful for the staff of the ICU?

The FS-ICU takes ten-to-fifteen minutes to complete. The FS-ICU has been validated in multi-centre studies and cross-cultural cohorts in the USA, Canada and the UK (Heyland et al. 2002, Dodek et al. 2004, Wall et al. 2007, Ferrando et al. 2019). In addition, detailed descriptions of the instrument and its characteristics have previously been published (Kentish-Barnes et al. 2009). Internal consistency ranges from 0.88 – 0.92, and test-retest reliability for 25 family members at 7 – 10 days was 0.85 (Heyland et al. 2002).

The FS-ICU was chosen for use in this study as a key component in the assessment of quality of care in the ICU is the measurement of family satisfaction. The Cronbach's alpha co-efficient for the total FS-ICU was 0.887 (very good), the satisfaction with care subscale was 0.869, and satisfaction with decision-making was 0.740 (respectable).

3.8.5: Pilot of psychometric assessments

I invited two family members to assist in pre-testing all three self-report questionnaires to assess their usability and time to complete. I took 20 minutes to self-complete the three questionnaires, and the two family members took 20 minutes and 25 minutes, respectively, to self-complete the same three questionnaires. This result is consistent with those found by Mishel (1983), Spielberger (1989) and Kentish-Barnes et al. (2009). Family members reported that they found the questionnaire items understandable and easy to complete.

3.9: Data collection procedure

Within 48 hours of the patient's admission to ICU, following initial admission assessment, treatment and stabilisation, eligible first-degree family members of each critically ill patient were invited in person by the research nurse to participate in the study. Each family member was given a verbal explanation and written participant information sheet outlining the purpose of the study (**Appendix X**). Opportunities were given for family members to ask questions regarding the study prior to study enrolment.

Written consent was obtained up to 48 hours after the patient's admission from each family member by the research nurse and was documented on the participant consent form (**Appendix XI**). This allowed a period of 24 hours

between information provision and requesting signed consent, enabling time for families to consider their participation in the study during a stressful time in their lives.

Following the providing of written consent, each family member was invited by the research nurse to complete the three baseline pre-test questionnaires: the State Trait Anxiety Inventory (STAI), Parents' Perception of Uncertainty Scale-family (PPUS-FM), Family Satisfaction-ICU (FS-ICU), and socio-demographic data (**TP1**). These were distributed by the research nurse to each family member and were completed away from the bedside in one of two dedicated private interview rooms within the ICU. After completion of the questionnaires, each family member was assigned to the intervention or control group sequentially (intervention group, then control group, then intervention group, and so on), by the research nurse. The completed screening and recruitment log ensured that group allocation was recorded and allocated correctly (**Appendix VI**). Family members were informed which group they had been assigned to (intervention or control) after completion of the three questionnaires at TP1.

3.9.1: Control group

The family members allocated to the control group received usual routine care and experienced the existing family informational support already operational in the ICU study site. There was variation in communicating with families within the ICU; it was predominantly based on the medical staff's individual methods/preferences, family requests, and the patient's clinical condition. The research nurse explained to the family member that they would receive updates of their relative's progress by medical and nursing staff, as and when they required them.

When a meeting had taken place, the ICU consultant undertaking the meeting completed a synopsis of the meeting and filed it within the dedicated family section in the patient's ICU medical notes, as per usual clinical practice. This information was documented on blue paper, in line with the study site's family communication practice across all in-patient ward areas.

3.9.2: Intervention group

The family member assigned to the intervention group received three tools, which made up the family meeting toolkit initially developed by Nelson et al. (2009), and which were adapted for this study, as outlined in **Chapter 4**. The family meeting planner (Tool 1 – pre-meeting tool) was kept in the family section of the patient's medical notes to track essential steps and the dates on which meetings had taken place or were going to be held. The family meeting guide template (Tool 2 – pre/during-meeting tool) was given to the family member in person by the research nurse at the earliest opportunity, once written consent had been received. They were given a verbal explanation regarding the purpose of the template, which was to assist them in preparing for the meeting and for note-taking during the meeting if they required. The information exchanged between the ICU clinician and family member(s) at each meeting was documented by the clinician on the medical documentation template (Tool 3 – post-meeting tool).

A scheduled family meeting was carried out within 72 hours of the patient's admission to ICU and weekly thereafter until their transfer from ICU to ward-based care. The family meetings were held away from the bedside in one of two dedicated private family interview rooms situated within the ICU.

The objectives were:

- 1) To review, with the family, the patient's current diagnosis and treatment recommendations,
- 2) To agree on the goals of care and criteria upon which the success or failure of these goals would be judged,
- 3) To discuss the patient's and family's needs, and
- 4) To establish the family's knowledge and understanding of the information presented.

The family member could invite other relatives to the meeting, if they wished. To encourage intervention fidelity, clinicians delivering the intervention followed the specific toolkit format.

The information exchanged with the family member(s) at each meeting was documented by the clinician on the medical documentation template (Tool 3 of the toolkit). Given the complexity and potential instability of ICU patients, weekly structured family meetings were held to ensure families were updated regularly. Should a change in the patient's condition have occurred before this time, the family meeting date and outcome of the meeting would be documented as per the format of the first meeting.

3.9.3: Pre-Discharge from ICU

The research nurse liaised daily with the nurse-in-charge regarding potential patients whose family member was involved in the study and who were making the transition to ward-based care. Once identified as being suitable for ward transfer, the research nurse contacted the same key family member who completed the questionnaires at TP1, either by telephone or face-to-face when

visiting their relative. They were invited by the research nurse to self-complete the same three questionnaires (STAI, PPUS-FM and FS-ICU) at time-point 2 (TP2). The questionnaires were required to be completed prior to ICU discharge, as, outwith this time-frame, the relatives may have reduced recall about ICU and may focus on ward-based care, which could have had an impact on their responses.

3.10: Data handling and statistical analysis

Analysis of quantitative data involves some statistical manipulation. A suggested simple approach is to first report on each of the individual variables (Polit and Beck 2017), using frequency distributions and graphical displays, such as bar charts, histograms or pie charts, which highlight the composition of the sample. Thereafter, more detailed summary statistics may be used, including measures of central tendency (mean, mode and median), measures of variability (range of scores), and measures of the spread of scores around the mean (variance and standard deviation). These simple measures will ensure the accurate organisation of the data, and provide a descriptive account of the study findings that are easy to understand (Polit and Beck 2017).

The aim of this study and its research questions directed the data analysis methods. Descriptive and inferential statistics were used to summarise socio-demographic and clinical data and questionnaire variables. I entered the raw data into the Statistics Package for Social Scientists (SPSS) for Windows, version 23.0 (IBM Corporation 2015).

Two initial processes are required to ensure accurate formal data analysis: data entry, and data checking. Data errors can arise from typing mistakes at entry or

from executing incorrect computer commands, and it is important to visually check for both possibilities (Polit and Beck 2017). Double data entry is advised to reduce errors and identify outliers (Polit and Beck 2017). These two processes were undertaken for the raw data from all three questionnaires being entered into SPSS in this study, as I was a novice in this area. Only the family members who completed both admission and discharge questionnaires were retained; incomplete data sets were deleted from the database (intervention group $n=12$, control group $n=11$; see **Figure 2**). All data were disposed of in accordance with requirements of the General Data Protection Regulations (2018).

3.10.1: Statistical analyses

Quantitative data analysis was used to examine family members' and patients' data collected on admission to ICU (TP1) and on discharge from ICU (TP2).

First, descriptive and inferential statistics were used to summarise the socio-demographic and clinical variables. Continuous data were summarised using means and standard deviations (SD), or median and ranges, as appropriate. Categorical data were presented as frequencies and percentages ($n/\%$) (e.g., gender, relationship to patient, previous ICU experience, living arrangement, nature of admission, expected/unexpected reason for ICU admission). Patients' clinical variables, such as Acute Physiological, Age, Chronic Health Evaluation (APACHE) III, length of patient stay, and frequency of visits by relatives, were reported as means/SD or $n/\%$, as appropriate.

Second, comparisons between the patient's and family members' socio-demographic characteristics at TP1 were computed for the intervention and control group using the **independent sample *t*-test**, when: 1) The level of data

was continuous (interval or ratio), and 2) data were normally distributed.¹ When the data were categorical (nominal, ordinal or dichotomous), the Chi-square test (χ^2) was used for comparisons (Polit and Beck 2017). Frequency histograms are presented for anxiety (state and trait), uncertainty, and family satisfaction overall with care and decision-making, to also show the distribution, i.e., the spread of the data, at TP1 (Polit and Beck 2017) (see **Appendix XII, Figures 16–21**). The non-parametric **Mann–Whitney U test** was used when the data were not normally distributed.

Thirdly, to determine how the control group and intervention group variables **changed** from TP1 to TP2, median scores and ranges are displayed graphically by **boxplots**, which are particularly useful for displaying the median scores and for making comparisons among groups (Polit and Beck 2017).

Finally, the Friedman **one-way Analysis of Variance** (ANOVA) for independent groups was used to explore changes over time in the control and intervention groups for the study variables (i.e., anxiety, uncertainty, degree of satisfaction overall with care and with information/decision-making) (time x group effect) (Polit and Beck 2017). Statistical significance was set at $p < 0.05$.

Two researchers (myself and the lead ICU clinician) reviewed the responses to the three free-text questions, 14 through 16, on the family satisfaction instrument, and identified common themes reported by family members for each question. A further ICU clinician was available to carry out a separate review of the free-text answers if discrepancies were found.

¹ The Shapiro–Wilk test was used to assess whether the data were normally distributed, as this test is more appropriate for small sample sizes (Polit and Hungler 2017).

A statistician was consulted at the University of Stirling for advice and support on data analysis and presentation.

3.10.2: Sample size requirements

The sample size for the study reduces the probability of a sampling error and was determined by power analysis (Polit and Beck 2017). To detect a difference between the group means of 11, with a common standard deviation of 14, 5% probability of type 1 error and 80% power, the sample size required was 26 participants per group. The effect size to detect differences of 11 points between mean control satisfaction and mean intervention satisfaction scores with a standard deviation of 14 was based on previous published research (Heyland et al. 2002, Hunziker et al. 2012, Schwarzkopf et al. 2013, Hwang et al. 2014).

3.11: Ethical considerations

3.11.1: Research Ethics Committee

In order to advance with any research, clinical audit or service evaluation, advice should be sought from the local NHS Research and Development department in the first instance (Nursing and Midwifery Council 2008). NHS Forth Valley (NHS FV) research and development (R&D) department were provided with full details of the study and correspondence confirmed that the research study did require NHS FV R&D approval. The West of Scotland Research Ethics Service were also informed of the study and verified that the study did require ethical review under the terms of the Governance Arrangement for Research Ethics Committees. Subsequently, an Integrated Research Application System Application (IRAS) form was completed and submitted.

The West of Scotland Research Ethics Committee (REC) granted approval of the study in April (2016), and NHS FV R&D approval in June (2016). The University of Stirling School of Nursing and Midwifery confirmed sponsorship. It is worth noting that, since these approvals were obtained, the School has been re-named the Faculty of Health Sciences and Sport, if needed for verification of the ethics application and approval process (see **Appendices XIII-XVI**).

3.11.2: Informed consent

As outlined in Section 3.10, family members were provided with a verbal explanation and written information sheet regarding the study by the research nurse and advised that their participation was entirely voluntary (**Appendix X**). They were assured that a decision of non-participation or withdrawal from the study would not affect in any way the quality of care delivered to their relative. Should the family member decide not to complete the pre-discharge questionnaires, their data on their questionnaires completed at TP1 were discarded and not used in any further analysis.

3.11.3: Family members' risks

There was the possibility that the family members may become distressed as a result of participating in the study and having a loved one admitted into the ICU. The aim of introducing the communication strategy, i.e., the family members' toolkit, was to meet the informational needs of the families. In the event that a family member became distressed, questions were asked by the research nurse as to the availability of immediate or ongoing support from other family members or friends. If the research nurse, who also had many years of ICU clinical experience, felt it was necessary, or if the participant requested, a referral was made to the hospital Chaplain for additional support. The hospital Chaplain was

considered to be the best person to contact, as he was trained in providing emotional support to family members within the ICU and visited the ICU daily. The participants were also provided with the details of the only UK-based ICU support group, icusteps.org, which provides support to families affected by critical illness.

There was the possibility that the family members may have felt uncomfortable completing sensitive questions within the questionnaires. They may have also felt anxious being away from their loved one's bedside to complete the questionnaires. They were reassured by the research nurse that the ICU operated an open visiting policy. There were no restrictions to visiting times, and completion of the questionnaires would not directly restrict the time that they could have spent with their relative. They were also offered the opportunity to complete the questionnaires one at a time, which further reduced the length of time away from their relative's bedside.

There was a small risk that completing multiple questionnaires could lead to fatigue, which can be particularly problematic in studies involving the families of the severely ill, as they are already enduring high levels of stress (Ben-Nun 2008).

Family members were recruited once their relative's condition was stable. However, a patient's journey within the ICU is often unpredictable and fluctuates daily, depending on their severity of illness. There was the possibility that the patient may not survive for the duration of the study. If this unfortunately occurred, the patient's details were documented in the dedicated ICU bereavement team's

diary and the family was offered further support, as guided by this service. The data from these participants were not utilised in any further analyses.

3.11.4: Patients' risks

No patients were recruited to this study. Patient data were extracted from routine patient records by the ICU research nurse (**Appendix VIII**). There were no additional research-specific patient procedures or follow-up when patients were discharged from ICU.

3.11.5: Confidentiality and anonymity

Confidentiality and anonymity were given great consideration throughout the research process. All family members were advised that participation in the research study was entirely voluntary. All data were collected, processed and stored immediately for the purposes of the study and would remain strictly confidential at all times and comply with Good Clinical Practice guidelines (Medicines and Healthcare Products Regulatory Agency (MHRA) 2012) and the General Data Protection Regulations (2018). Caldicott Guardian approval was granted and approved by NHS Forth Valley, and Caldicott principles were maintained at all times (**Appendix XVI**).

Only I had access to statistical information stored on my personal laptop computer, which was also password-protected. Any removable storage devices used were encrypted, as per NHS Forth Valley hospital policy. The data collected on paper were stored immediately in a locked cabinet within the ICU research room, accessible only to me and the dedicated ICU research nurse. Paper or electronic records did not contain any patient-identifiable data. The NHS Code of

Confidentiality and NMC Code of Conduct was strictly adhered to throughout the study.

3.11.6: Investigator bias

The study site was my place of work. Investigators who conduct any type of study in their own environments are faced with unique challenges (Asselin 2003). Asselin (2003) points out that, when the researcher is already familiar with the setting, issues regarding expectations, past experiences, beliefs, and emotions can prevent them from achieving the detachment necessary for analysing data objectively. Cumulatively, these issues could hamper the validity of the findings. My role as researcher was kept separate from my managerial roles and responsibilities within the ICU. The recruitment of participants, data collection and management of the study was undertaken by the dedicated ICU research nurse, who had no clinical role or input into the delivery of care to the patients within ICU.

The three free-text questions asked how to make the ICU care better, what the staff did well, and any comments that may be helpful. In order to avoid confirmation bias, where a researcher interprets the data to support their hypothesis, two researchers (myself and the lead ICU clinician) reviewed the written responses to these questions separately (Creswell and Creswell 2018). Common positive and negative descriptors were identified and organised into categories, based on previously reported themes published by Henrich et al. (2011) and Schwarzkopf et al. (2013). A further ICU clinician was available to carry out a separate review of the free-text answers if discrepancies were found.

CHAPTER 4: THE MODIFICATION AND TESTING OF THE INTERVENTION

4.1: Introduction

The intervention used within this study consisted of a family meeting toolkit. The toolkit is a planned set of activities which, when completed, aims to ensure the completion of a structured family meeting with ICU family members (Nelson et al. 2009, see **Appendix IV**).

4.1.1: Family meeting tools

There were three family meeting tools employed in this research study, organised by the stage of the family meeting, which were chosen to address the pre-meeting, during-meeting, and post-meeting stages, as follows.

Tool 1 – Pre-Meeting

The pre-meeting tool functioned as a checklist and included the logistical steps necessary for conducting the family meeting. For example, the tool assisted in identifying and inviting family members to be present at the meeting, identifying members of the healthcare team to participate, and confirming the time and location of the family meeting. The meeting planner was also time-defined, in that it specified certain steps to be undertaken in the days preceding the family meeting, such as scheduling the meeting within the first three days (72 hours) of admission to ICU.

Tool 2 – Pre/During-Meeting

The family meeting guide is a visual aid, prompting family members to reflect on their current knowledge, record any questions they may have, and document areas of concern in preparation for and during the family meeting (Nelson et al.

2009). The checklist aimed to help families organise their thoughts and prepare questions prior to the meeting. It included suggestions to be discussed during the meeting, such as reviewing what the family knew about their relative's illness and treatment, identifying topics for clarification with the medical and nursing teams, writing down concerns or fears to be shared, and identifying goals for the family meeting. This tool was developed using a literature review, expert consensus, and survey data (Nelson et al. 2009).

Tool 3 – Post-Meeting

The family meeting documentation template specifies key areas to be documented post-meeting in the patient's medical notes. This tool provides a central venue for other healthcare disciplines to view what has been discussed with the families regarding their relative's immediate and future care, and their treatment and potential prognosis. There is also a free-text section to document the family's understanding of the meeting content. Providing consistent information in this way has previously been found to lead to reductions in anxiety in family members whose relative is at high risk of dying in the ICU (Pouchard et al. 2001).

4.1.2: Modification of the tools in the toolkit

The family meeting toolkit was originally developed in the USA, therefore, prior to designing the research study, the toolkit in its entirety was forwarded to the lead ICU clinician and lead nurse to assess its potential for use within the study setting, the ICU. They suggested that modifications would be required, given the differences between the USA and UK healthcare systems. This process also aids with the toolkit's integration into clinical practice, because it initiates the

engagement of key clinicians (Pronovost et al. 2008). The author of the toolkit study was contacted on multiple occasions to gain permission to use it, with no response. However, in their publication, Nelson et al. (2009) wrote that, “for the present, we offer these tools as prototypes and encourage their adaptation to meet local needs and maximise acceptability and use” (p. 9).

The toolkit was emailed to all ICU clinicians ($N=10$) and a number of critical care nurses (one senior charge nurse, three senior staff nurses, and six junior staff nurses) ($N=10$) for comment on its relevance and to identify whether any further modifications were required. They were asked to comment on the toolkit overall, and, specifically, whether any of the questions were confusing, or whether they were too long or difficult to understand in any way. Family members who were visiting the ICU were asked whether they would assess and feedback on the usefulness of the family meeting guide. Five family members provided comments.

Tool 1 – Pre-Meeting modifications

Four suggestions were put forward for modifications to the Pre-Meeting tool:

- 1) The “Diagnosis” questions should be removed, as this was already documented on a dedicated ICU admission sheet and on the electronic dedicated ICU “Ward Watcher” database.
- 2) The timescale of the meetings should be reduced from 5 days to within 72 hours of patient admission. Based on other research studies, as described in Chapter 2, meetings conducted within 72 hours of admission to ICU are associated with reduced days spent in ICU and have been successfully introduced within the oncology setting and are appropriate for the ICU

setting (Mosenthal et al. 2006, Lautrette et al. 2007, Yousefi et al. 2012, Garrouste-Orgeas 2016). Furthermore, one study suggests that the first two-to-three days of ICU admission represents the time during which family members are most likely to perceive receiving inconsistent information from ICU care providers regarding the clinical care of those admitted (Hwang et al. 2014). Hence, delivering a communication strategy during this critical period may help reduce inconsistencies.

- 3) Subsequent dates of meetings should be inserted to provide a quick visual display for all the healthcare team of when meetings were undertaken.
- 4) The key contact person's details and telephone number of the patient should be documented on the planner again for quick reference.

Tool 2 – Pre/During-Meeting

Minor changes were made to the Pre/During-Meeting tool, for example, families asked that the additional documents sentence (for example, "living will") was omitted. This was also requested by ICU clinicians and nursing staff, who requested that the list of healthcare team members to be present at the meeting was also omitted (see below). These steps enhanced their understanding of the guide and ensured that it was both appropriate and relevant to ICU families in this study.

Tool 3 – Post-Meeting

The main changes made to the family meeting documentation template (the Post-Meeting tool) were to:

- 1) Remove items such as social worker, palliative care consultant, chaplain as, in this ICU, the family meetings are mainly conducted with the ICU clinicians and nurse caring for the patient. Should another individual be present, for example, a surgeon, medical consultant or social worker, the ICU team would document this on the documentation guide.
- 2) Emotional and psychological symptoms interfere temporarily with a family's ability to listen to, understand and absorb what is being said especially during a meeting held in the initial acute phase of illness (Pouchard et al. 2001). Thus, evaluation and re-evaluation of the families understanding of their relative's admission and clinical condition at both the onset and end of the meeting was deemed necessary.

4.1.3: Pre-testing of toolkit

The feedback from clinicians, nursing staff and patients' families on the family meeting toolkit were brought together, cumulating in an adapted toolkit (**Appendix XVII**). Prior to conducting the main study, there was pre-testing of the adapted toolkit to be used in this study. A summary of the aim, methods, results and conclusion of this pre-test pilot study are presented below.

Aim: To identify the practicalities involved in holding and documenting family meetings using the adapted documentation tools.

Subjects and methods: Piloting involved the adapted toolkit in its entirety being used before, during and after family meetings with two ICU consultants, the bedside ICU nurse, and four family members of four ICU patients.

Results: Family and ICU consultant/nurses provided feedback from the pre-piloting, which reported that the reminder elements of the intervention (tool 1) helped towards the scheduling of delivering a family meeting. Family members were also positive with regards to the list of questions they were provided with prior to the family meeting; all four participants took them to the meeting (tool 2). ICU clinicians reported that the documentation template covered the key areas to be discussed with families (tool 3). ICU nursing staff expressed that there was more structure to their communication with the families who attended the family meetings.

Conclusion: Pre-testing was extremely useful because it helped to identify whether the toolkit was feasible to use within the ICU study site. Family members and the ICU medical and nursing team found the tools clear and understandable to use.

Following modification and piloting of the family meeting toolkit, it was subsequently employed for the main study. A presentation of the results of the analysis of the data gathered with this toolkit will follow.

CHAPTER 5: RESULTS

5.1: Introduction

This chapter presents the results of the study, firstly presenting the patients' socio-demographic characteristics and clinical variables. Secondly, the family members' own characteristics and how these differed for the control and intervention groups are presented. Thirdly, the descriptive and inferential statistics, used to address the overall aim of the study and research questions, are also presented.

To reiterate, the aim of the study was to evaluate the effects of delivering a structured communication strategy on anxiety (state and trait), levels of uncertainty in illness, and satisfaction overall with care and decision-making in families of critically ill patients in the ICU setting.

Two research questions were identified to address this aim:

- In family members of ICU patients, how did the control group and intervention group's state and trait anxiety, uncertainty in illness, and satisfaction overall with care and information/decision-making change from their relative's admission to ICU to discharge from ICU?
- What effect did the introduction of the intervention (i.e., communication strategy) have over time on the intervention group compared to the control group ICU family members' state and trait anxiety, uncertainty in illness, and satisfaction overall with care and information/decision-making (time x group effect)?

5.2: Participant flow and follow-up

Recruitment in the ICU ran over a 19-month period, July 2016 to February 2018. The CONSORT diagram (**Chapter 3, Figure 2**) shows that 458 patients were eligible for the study during this period, but the majority (349 patients) did not meet the initial inclusion criteria, and 25 family members declined to participate in the study. Family members were assigned to the intervention or control group sequentially (intervention group, then control group, then intervention group, and so on), by the research nurse. At TP1 (i.e., the patient's admission to ICU), 75 family members entered into the study, and 52 completed the questionnaire at TP2 (i.e., at the patient's discharge from ICU).

Thirty-eight family members were recruited to the control group (receiving routine care), with 26 family members completing the three questionnaires. This represents a retention rate of 68.4%. Thirty-seven family members were recruited to the intervention group (receiving the communication strategy), with 26 family members completing all three questionnaires. This represented a retention rate of 70.2%. Some family members had agreed to participate in the study but did not complete the questionnaires, either because their family member had died ($n=15$), or they were transferred to tertiary centres for specialist treatment ($n=9$).

5.3: Patients' socio-demographic and clinical information

5.3.1: Patient group comparison

Socio-demographic and clinical data were collected for the patients ($n=52$) of the family members who participated in the study on admission to ICU (TP1) and at discharge from ICU (TP2). There were no statistically significant differences

between the two groups in terms of their age, gender, APACHE score, length of hospital stay, admission expected/unexpected, and admission type (**Table 5**).

Table 5: Comparison of patient characteristics across study groups

	Patient characteristics			
	Study group			
	Control group (n=26)		Intervention group (n=26)	
Patient Age mean (SD) range	51.9 (15.9)	23–78	56.5 (15.5)	23–82
Gender (no/%)**				
Male	14 (54)		14 (54)	
Female	12 (46)		12 (46)	
APACHE mean (SD) range	19.27 (5.9)	12–34	18.80 (4.6)	10–28
Length of stay in days *	17.0	4–134	19.7	3–64
Admission (no/%)**				
Expected	1 (3.9)		2 (7.7)	
Unexpected	25 (96.1)		24 (92.3)	
Admission Type (no/%)**				
Medical	19 (73.1)		18 (69.2)	
Surgical	7 (26.9)		8 (30.8)	

Independent *t*-test; *Mann–Whitney-*U* test, ** Chi-square test; Fisher’s exact test

Despite patients in the control group being younger, with a higher APACHE score indicating a higher severity of illness, the differences between the groups were not statistically significant for age ($t -1.055$, $df 50$, $p=0.296$), or illness severity ($t .312$, $df 50$, $p=0.756$).

The patient's length of stay was 2 days shorter in the control group, compared to the intervention group (17 days versus 19 days); these differences were not statistically significant ($U= 267.5$, $p=0.196$).

The majority of patients in both the control group and intervention group were male (54%), admitted unexpectedly (>90%), and presented with a medical rather than a surgical condition (**Table 5**); differences were not statistically significant between genders ($p=0.609$), admission criteria ($p=0.500$), or admission speciality ($p=0.500$).

5.4: Family members' socio-demographic characteristics

5.4.1: Family group comparisons

Table 6 shows that the majority of family members were aged over 50 years and were female. The results indicate that there were no statistically significant differences between the control group and intervention group with regards to each family member's age ($t -1.509$, $df 50$, $p=0.138$), or gender ($p=.541$).

The family member's relationship to the patient prior to their admission to ICU, was mostly as a spouse or parent for both groups. The majority of family members in the intervention group had no previous experience of the ICU environment and lived within the geographical area of the hospital. In contrast, half of the family members in the control group had some previous experience of the ICU environment. These differences were not statistically significant for previous ICU experience ($p=.400$), the frequency of family visits ($p=.591$), or location of family member ($p=.267$).

Table 6: Comparison of family characteristics across study groups

	Family members' characteristics	
	Study groups	
	Control (n=26) N/%	Intervention (n=26) N/%
Age in years, mean (SD)*	50.4 (14.4)	55.3 (8.27)
Gender		
Male (no,%)	9 (34.6%)	6 (23.1%)
Female (no,%)	17 (65.4%)	20 (76.9%)
Relationship to patient (no ,%)		
Spouse	10 (38.4%)	11 (42.3%)
Parent	5 (19,2%)	4 (15.3%)
Previous ICU experience		
Yes	13 (50%)	9 (34.7)
No	13 (50%)	17 (65.3)
Location		
Town (where hospital located)	11 (42.3%)	16 (61.5)
Out of town	15 (57.7%)	10 (38.5)
Frequency of visits to patient		
More than weekly	16 (61.5)	16 (61.5)
Weekly	10 (38.5)	9 (34.7)
Monthly	0 (0.0)	1 (3.8)

Chi-square test; Fisher's exact test. *Independent *t*-test.

5.5: Changes in anxiety, uncertainty in illness and satisfaction with care scores between TP1 (admission to ICU) to TP2 (discharge from ICU)

The change in levels of (state and trait) anxiety, uncertainty in illness, and satisfaction overall with care and decision-making scores for the control group and intervention group were compared from admission to ICU (TP1) to discharge from ICU (TP2) using boxplots (**Table 7**). For ease of reporting, each

questionnaire, used to measure anxiety, uncertainty in illness, and family satisfaction scores, is reported separately and in sequence.

Table 7: Comparison of family members' anxiety, uncertainty in illness and satisfaction with care and information/decision-making for the study groups on admission to ICU and discharge

Variables (median, range)	Admission to ICU (TP1) Study group		Discharge from ICU (TP2) Study group	
	Control	Intervention	Control	Intervention
Anxiety:				
State	51.5 (28–71)	51.0 (27–69)	47.0 (26–70)	49.0 (24–69)
Trait	46.5 (23–53)	44.0 (26–61)	44.5 (23–57)	41.0 (24–67)
Uncertainty	76.5 (42–99)	80.0 (46–118)	75.0 (45–119)	67.5 (50–98)
Satisfaction with:				
Overall score	84.9 (60–91)	81.8 (59–89)	87.5 (58–92)	84.3 (65–94)
Care	92.8 (69–100)	91.0 (67–100)	93.7 (57–100)	91.6 (67–100)
Information/ Decision-making	70.2 (40–80)	72.6 (47–80)	73.7 (47–87)	71.5 (50–87)

5.5.1: STAI-state (S) anxiety questionnaire

Changes in the **state anxiety** scores were examined between TP1 and TP2.

There was a change in the median score of a reduction of 4.5 points in state anxiety from TP1 to TP2 in the control group; and a 2-point reduction in state anxiety scores in the intervention group from TP1 to TP2.

Higher scores indicated higher state anxiety levels (Spielberger et al. 1983). The distribution of state anxiety scores for these groups is shown in the boxplot in **Figure 3**.

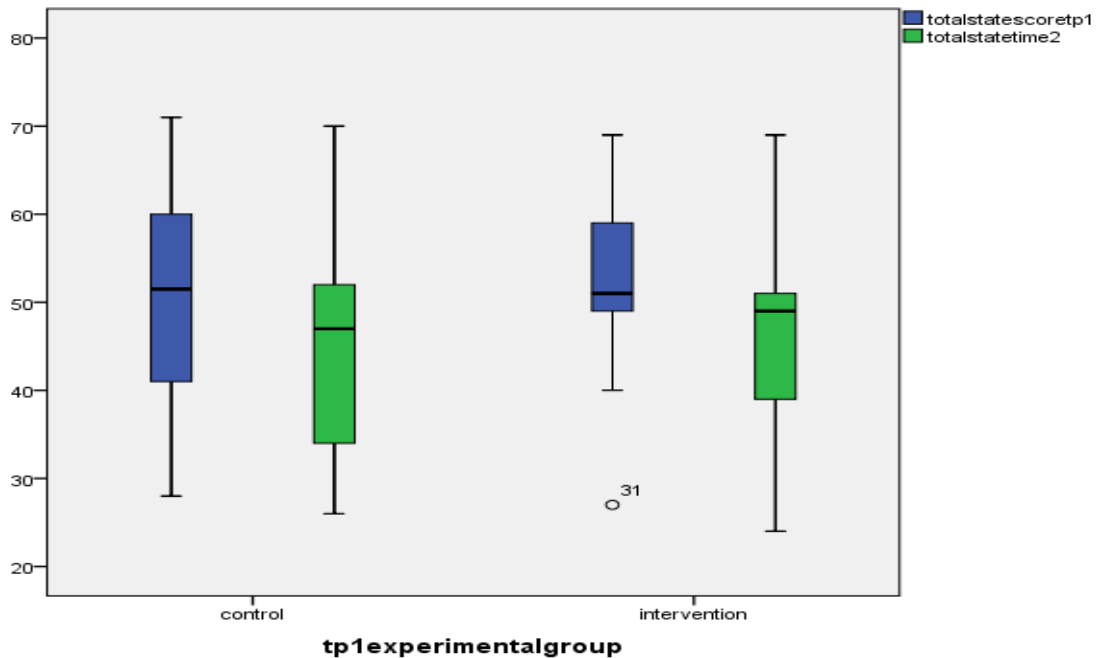


Figure 3: Changes in state anxiety scores between TP1 and TP2 by study group

Figure 3 displays the median, the interquartile range (IQR), and the smallest and largest values for state anxiety scores for each study group. The distribution of state anxiety median scores is spread wide in both control and intervention groups at TP1 to TP2; almost the full range of possible anxiety scores is seen. Whilst there was variability within the control and intervention group scores, 50% of scores remained within the moderate anxiety (38–44) to high anxiety (45–80) range (Spielberger et al. 1983).

5.5.2: STAI-trait (T) anxiety questionnaire

When **changes** in the **trait anxiety** scores were examined between TP1 and TP2, the results indicated that trait anxiety scores were in the high range on admission. Median scores decreased by 2 points (control) and 3 points

(intervention) on discharge to within the moderate trait anxiety range (Spielberger et al. 1983).

Figure 4 demonstrates that the median spread of trait anxiety scores was similar at TP1 and TP2 in the control group; and the median changes from TP1 to TP2 in the intervention group were also similar.

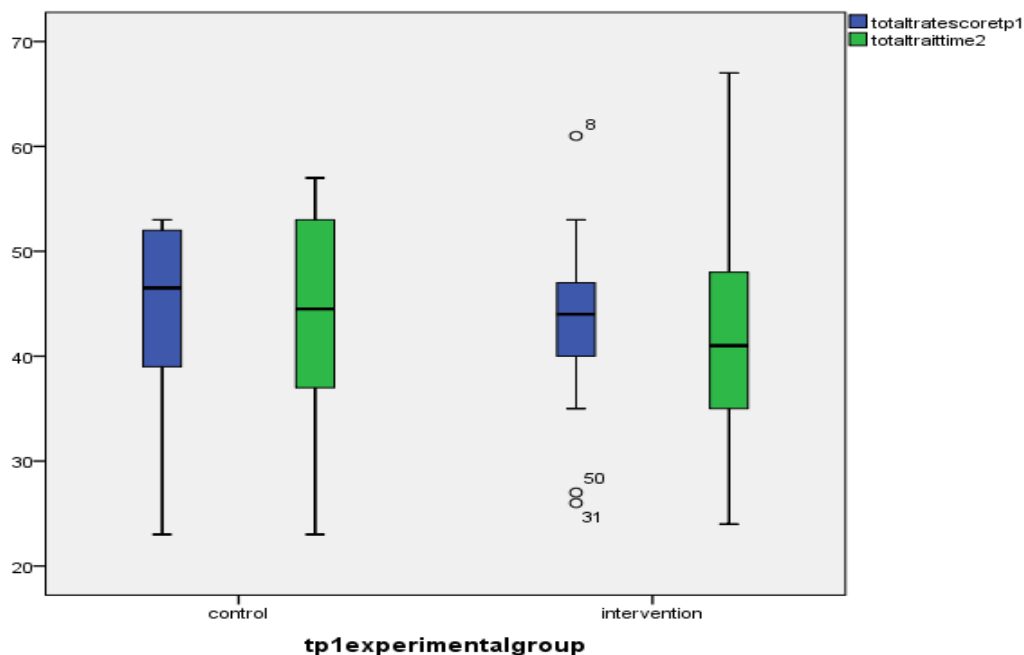


Figure 4: Changes in trait anxiety scores between TP1 and TP2 by study group

The distribution of the trait anxiety scores were more concentrated at TP1 and widened at TP2 in the intervention group, compared to the control group. There were 3 outlying data points which differed from other scores in the intervention group at TP1: 2 low trait anxiety scores, and 1 high trait anxiety score.

5.5.3: Uncertainty in illness (PPUS-FM questionnaire)

When the **change** in the **uncertainty in illness** scores were examined, total uncertainty in illness scores ranged from 42–119; higher scores indicate higher levels of uncertainty (Mishel 1983). The median uncertainty scores at both TP1

and TP2 in the control group were nearly identical. In contrast, the change in median uncertainty in illness scores from TP1 to TP2 in the intervention group reduced by 12.5 points but did not reach a level of significance. The range of uncertainty in illness scores is spread wide in the intervention group at TP1 and in the control group at TP2, where almost a full range of scores is seen (45–119 intervention, versus 46–118 control) (**Figure 5**). At TP2, the upper uncertainty in illness range reduced in the intervention group (50–98), whereas, in the control group, the upper range increased by 20 points, to the maximum score of 119.

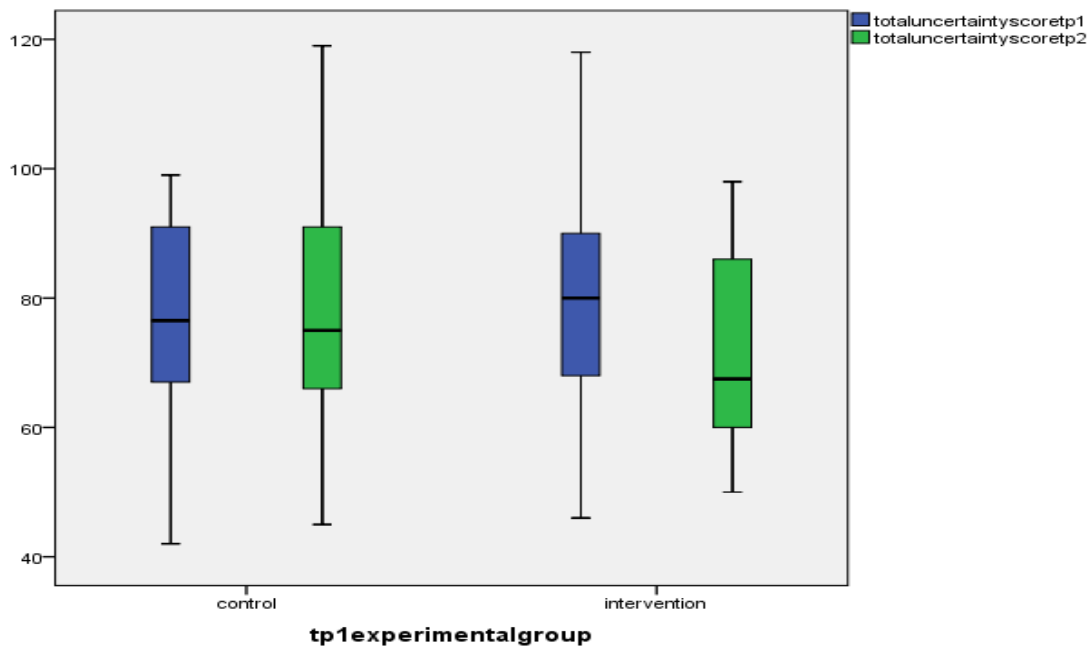


Figure 5: Changes in uncertainty in illness scores between TP1 and TP2 by study group

5.5.4: Overall family satisfaction (FS ICU questionnaire)

When the **change in family satisfaction (overall score)** at TP1 and TP2 were examined between the control and intervention groups, family satisfaction scores range from 0 to 100, with higher scores indicating higher satisfaction overall with either care or decision-making. The change in the overall satisfaction scores from TP1 to TP2 in the control group, and in the intervention group, increased by 2.6

points (control) and 2.5 points (intervention) and did not reach a level of statistical significance. These results indicated that family members in both the control and intervention group were overall highly satisfied with their ICU experience.

The control group's overall satisfaction scores are more widespread at TP1 and become less so at TP2 (**Figure 6**). In contrast, in the intervention group, satisfaction scores were closer to the median score and therefore less spread out at both TP1 and TP2. There were 2 outlying low scores for the intervention group at TP1.

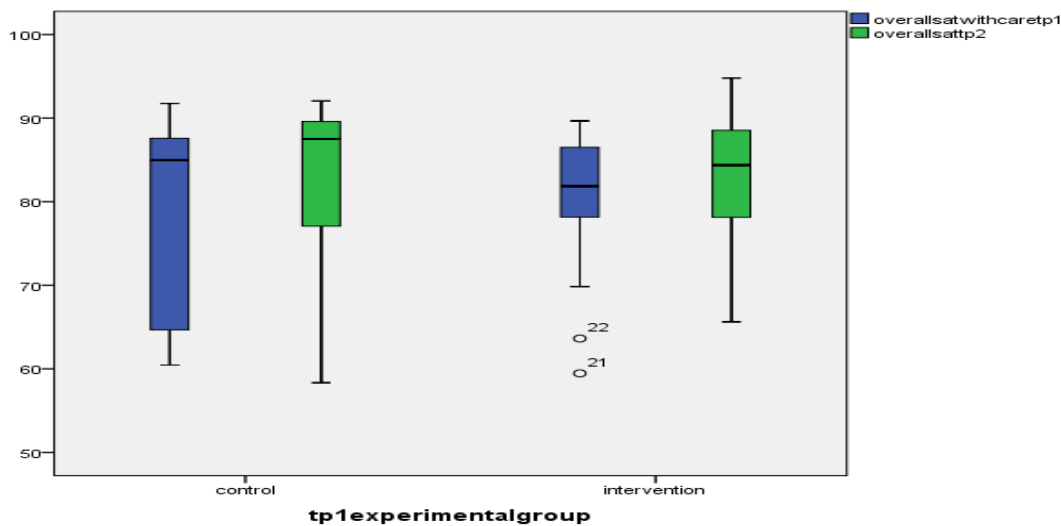


Figure 6: Changes in overall satisfaction scores between TP1 and TP2 by study group

5.5.5: Family satisfaction with care

The **changes in family satisfaction with care** for the control and intervention groups were examined. The results demonstrate that family members experienced high satisfaction with care throughout their ICU journey.

Changes in median satisfaction scores from TP1 to TP2 in the control and intervention groups were similar (**Figure 7**). Satisfaction with care in the control

group was more widespread at TP1 and less widespread at TP2. A similar pattern was seen in the intervention group scores. Each group had outlying data points; 4 with low scores, and 4 with extremely low scores, all at TP2.

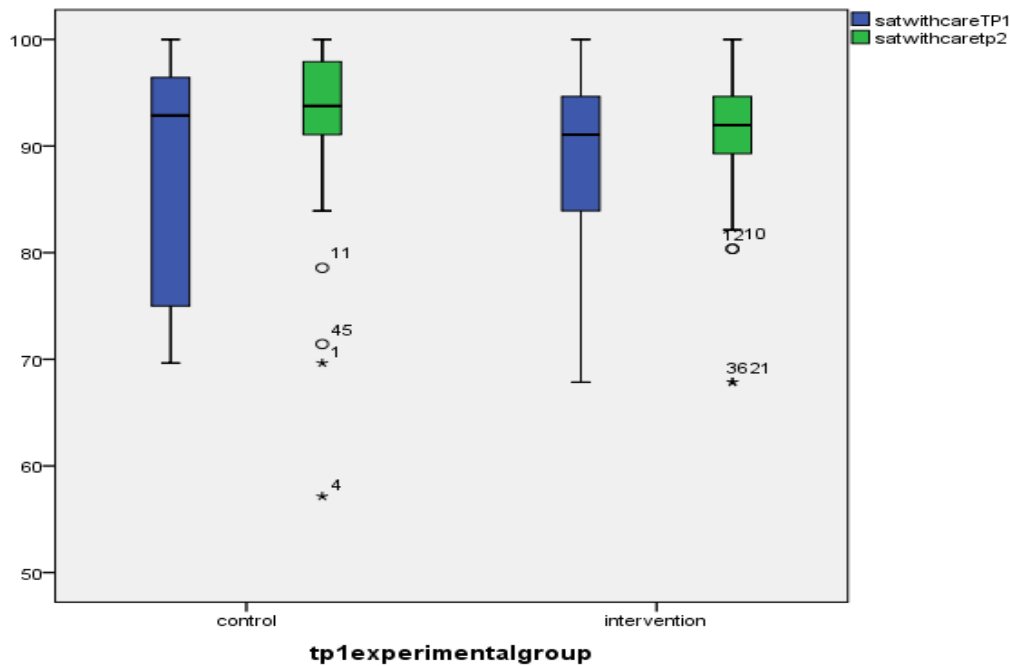


Figure 7: Changes in satisfaction with care scores between TP1 and TP2 by study group

5.5.6: Family satisfaction with information/decision-making

The changes in family satisfaction with information/decision-making between TP1 and TP2 were examined. The results showed that family satisfaction with information/decision-making was lower and in the “mostly satisfied” rather than the “highly satisfied” range. A median change score of an increase (3.5 points) in family members’ satisfaction with information/decision-making was shown in the control group. In contrast, the median change scores for the intervention group between TP1 and TP2 showed a decrease (1.1 points).

Satisfaction with information/decision-making scores in the control group were more widespread at TP1 than at TP2 (Figure 8). In contrast, in the intervention

group, satisfaction scores at TP 2 were more widespread than at TP1, with 2 outlying low scores at TP1.

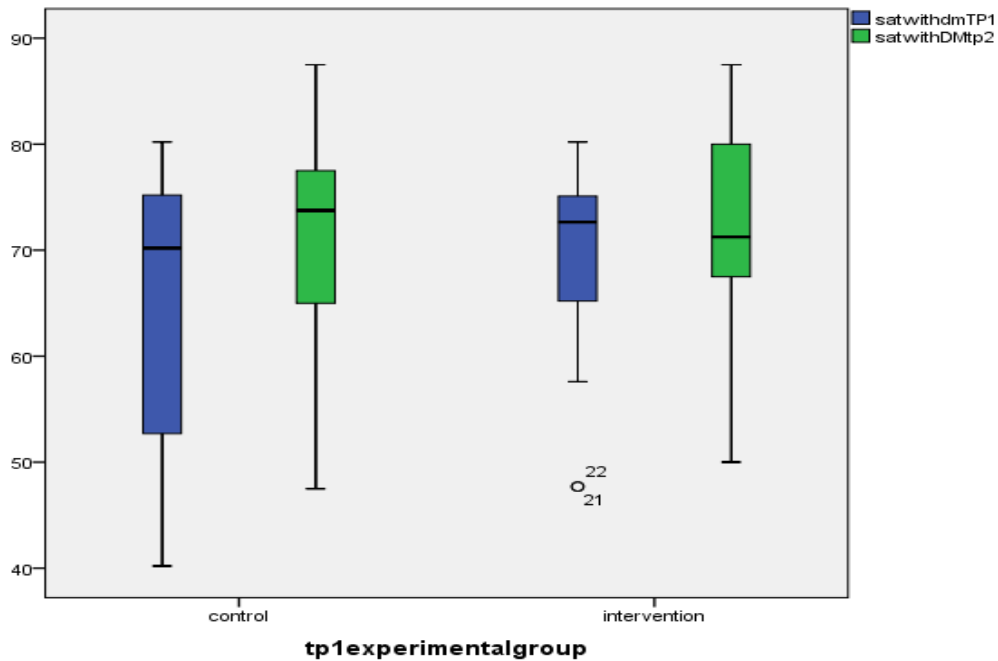


Figure 8: Changes in satisfaction with information/decision-making scores between TP1 and TP2 by study group

5.6: Differences between family members’ anxiety, uncertainty in illness, and satisfaction with care and information/decision-making between both groups over time

In this study, the differences in anxiety (state and trait), uncertainty with illness, and satisfaction (overall satisfaction, and satisfaction with care and information/decision-making) between the two groups were examined over time (i.e., at admission to ICU (TP1) to discharge from ICU (TP2)). Because the normality assumptions for carrying out a repeated measures analysis of variance were not met, the Friedman one-way ANOVA, non-parametric test was used to compare change over time in each group.

5.6.1: State and trait anxiety

Using Friedman’s analysis of variance (ANOVA), the reduction in state anxiety over time was statistically significant (Friedman’s $Q=10.0$, $df 1$, $p=0.002$, $W=.192$) (Table 8). Post-hoc analysis with Wilcoxon signed-rank tests was conducted with a Bonferroni correction applied, resulting in a significance level reset at $p=0.025$. There were no statistically significant differences in state anxiety scores found over time following the Bonferroni correction ($Z=-2.999$, $p= 0.03$). The line graph was useful here in that it indicates that, although not statistically significant, there was a trend whereby the intervention group’s state anxiety score at TP2 showed less of a reduction when compared to the control group’s state anxiety score (Figure 9).

Table 8: State anxiety differences over time

Hypothesis Test Summary				
	Null Hypothesis	Test	Sig.	Decision
1	The distributions of totalstatescoretp1 and totalstatetime2 are the same.	Related-Samples Kendall's Coefficient of Concordance	.002	Reject the null hypothesis.

Asymptotic significances are displayed. The significance level is .05.

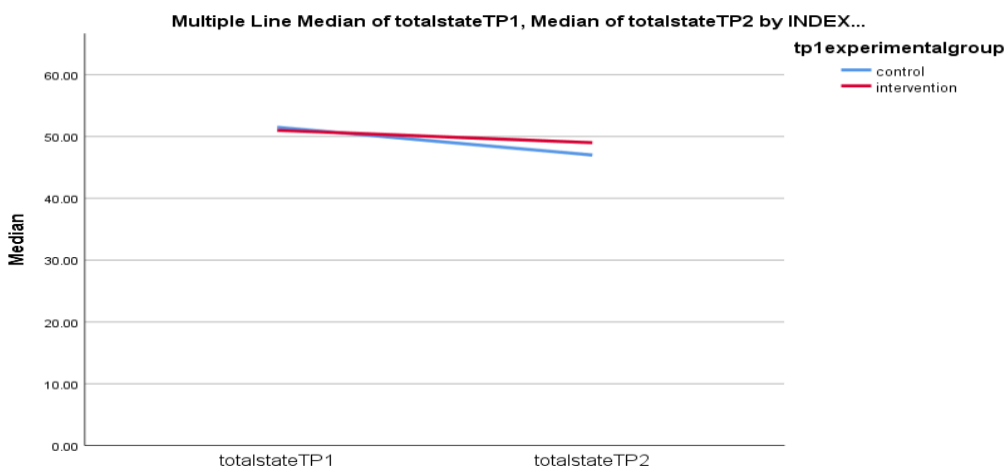


Figure 9: State anxiety scores at TP1 and TP2 by study group

In contrast to state anxiety, there was found to be no statistically significant difference over time in trait anxiety scores for both the control and intervention groups (Friedman $Q=.100$, $df\ 1$, $p=0.752$). The line graph below (**Figure 10**) shows that there was little reduction in the control group and intervention group, supporting the notion that trait anxiety is a relatively stable characteristic over time (Spielberger 1983).

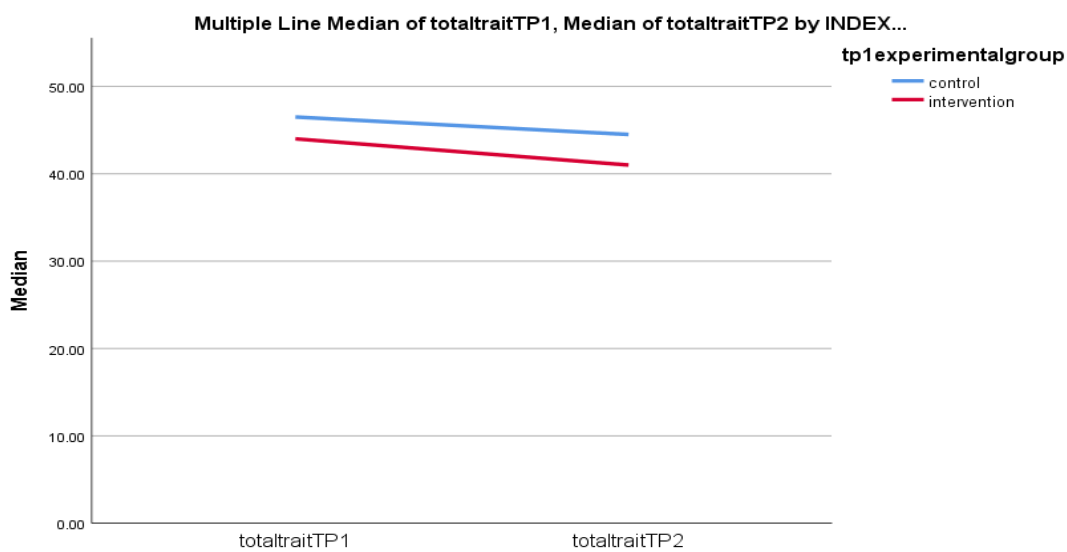


Figure 10: Trait anxiety scores at TP1 and TP2 by study group

5.6.2: Uncertainty in illness

The reduction in uncertainty in illness scores over time was not statistically significant (Friedman $Q=-1.643$, $df\ 1$, $p=0.100$). Despite the lack of statistical significance, **Figure 11** displays the level and direction of differences between uncertainty in illness scores for families in the intervention group at TP2, which were lower when compared to the control group's scores.

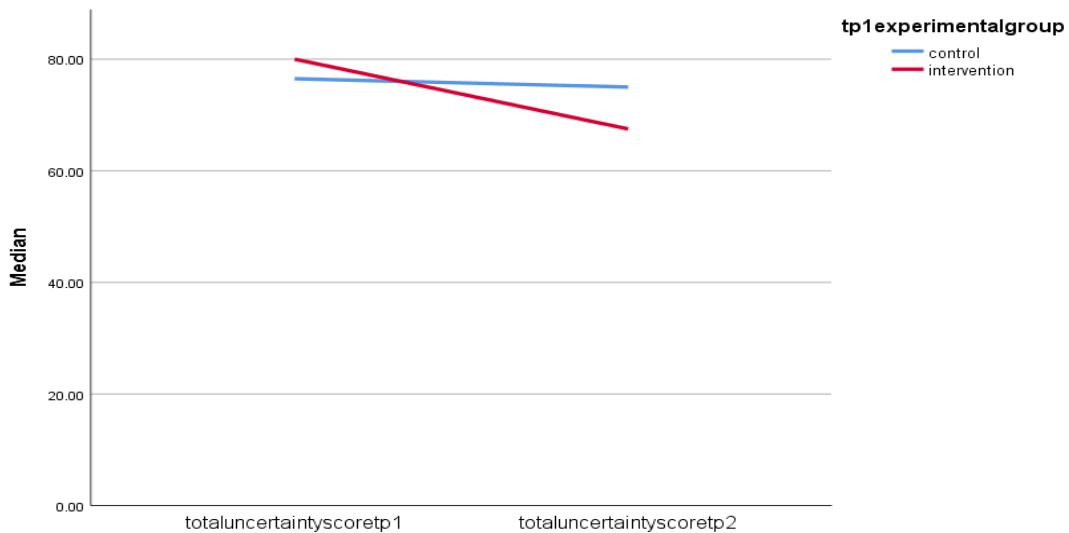


Figure 11: Uncertainty in illness scores at TP1 and TP2 by study group

5.6.3: Family satisfaction – overall, and with care

There was no statistically significant difference in overall family satisfaction over time (Friedman $Q=1.767$, $df 1$, $p=.077$). Similarly, there were no significant differences over time in family satisfaction with care (Friedman $Q=1.709$, $df 1$, $p=.087$). There was, however, a trend at TP2 for both groups to increase their satisfaction scores overall and with care (Figure 12 and Figure 13).

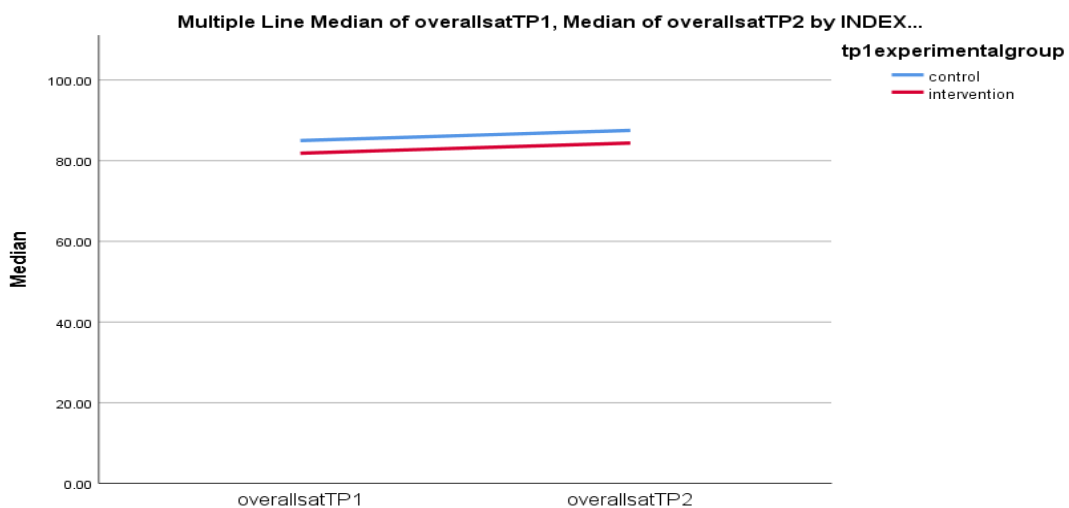


Figure 12: Overall family satisfaction scores at TP1 and TP2 by study group

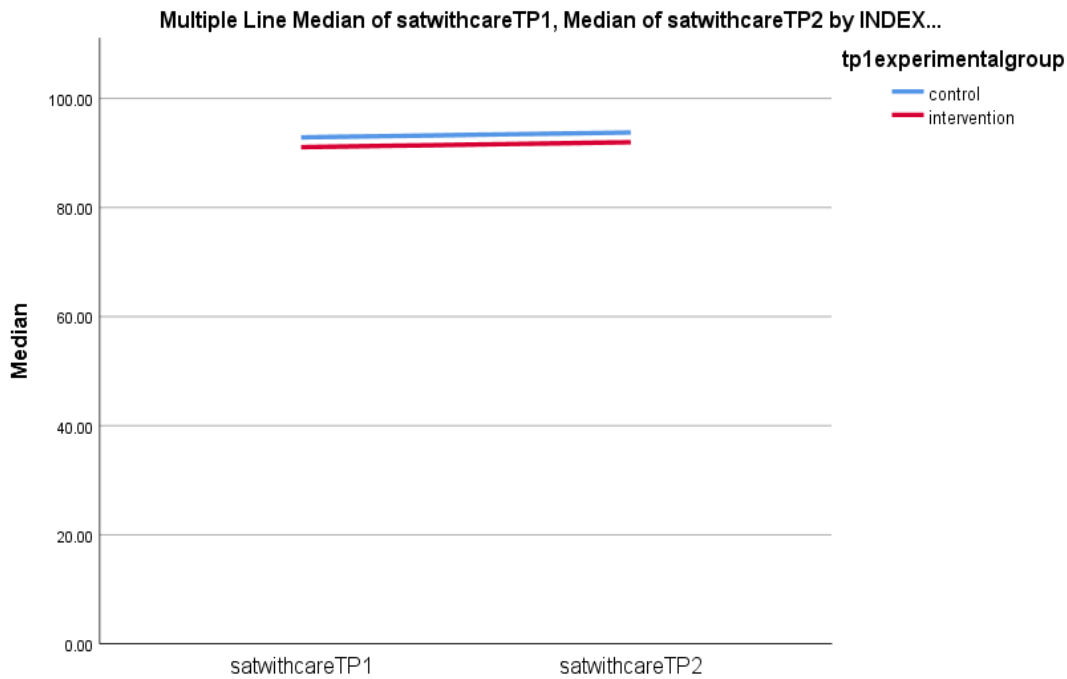


Figure 13: Family satisfaction scores at TP1 and TP2 by study group

5.6.4: Satisfaction with information/decision-making

There was no statistically significant difference over time in family satisfaction with decision-making (Friedman $Q=0.693$, $df 1$, $p=0.405$). However, it was shown that there was a tendency for families who received the intervention to be less satisfied with decision-making compared to those in the control group at TP2, although this did not reach a level of statistical significance (**Figure 14**).

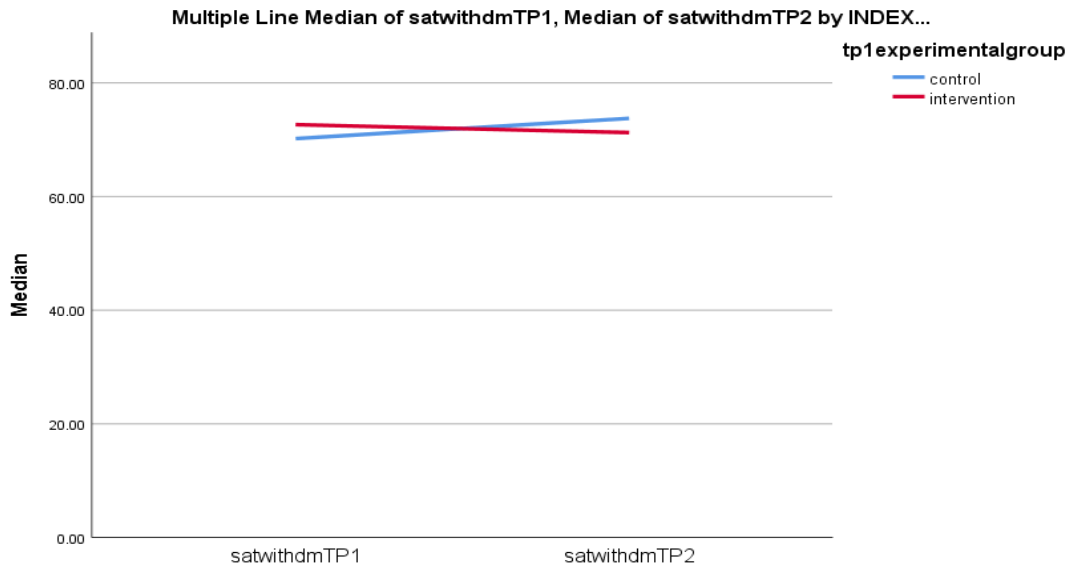


Figure 14: Satisfaction with information/decision-making scores at TP1 and TP2 by study group

5.7: Post hoc statistical power calculation

A post hoc power analysis calculation was conducted using the software package G*Power (Faul, Erdfelder, Lang and Buchner. 2007). The post hoc analyses showed that the statistical power in this study was 0.99 for detecting a medium effect size and above the minimum threshold value of 0.80. Thus, the achieved power for this statistical test to detect a medium effect size was sufficient (**Figure 15)**

F tests - ANOVA: Repeated measures, within-between interaction

Analysis:	Post hoc: Compute achieved power		
Input:	Effect size f	=	0.5
	α err prob	=	0.05
	Total sample size	=	52
	Number of groups	=	2
	Number of measurements	=	2
	Corr among rep measures	=	0.5
	Nonsphericity correction ϵ	=	1
Output:	Noncentrality parameter λ	=	52.0000000
	Critical F	=	4.0343097
	Numerator df	=	1.0000000
	Denominator df	=	50.0000000
	Power (1- β err prob)	=	0.9999998

Figure 15: Post hoc statistical power analysis

5.8: Qualitative comments from family members about their experiences in ICU

The FS-ICU questionnaire also asks family members whether they were **given adequate time** for questions and presents **three open-ended questions** regarding their experiences in the ICU, as follows.

- 1) Do you have any recommendations on how care in ICU could be improved?
- 2) Do you want to mention something we did well?
- 3) Do you have any further comments or recommendations that could be helpful for the staff of the ICU?

More family members in the intervention group at TP1 reported adequate time for questions and concerns to be addressed. Notably, both the intervention and control groups' family members sought more time at TP2 and prior to ICU discharge for their questions and concerns to be addressed (**Table 9**).

Table 9: Family response to having sufficient time for questions

Did you have adequate time to have your concerns addressed and questions answered?	Admission to ICU		Discharge from ICU	
	Study group (N/%)		Study group (N/%)	
	Control	Intervention	Control	Intervention
Adequate Time	14 (53.9)	17 (65.4)	8 (30.7)	5 (19.3)
More Time	12 (46.1)	9 (34.6)	18(69.3)	21(80.7)

Table 10 displays family members' free-text comments ($n=32$) for the three open-ended questions, questions 14 through to 16. The comments provided by family members to the three questions were classified into positive and negative descriptors. The responses were organised by two researchers (myself and lead ICU clinician) into the categories of communication, ICU staff, care delivery, and ICU environment, based on categories employed in two previous studies (Hendrich et al. 2011, Schwarzkopf et al. 2013).

Overall, positive comments outnumbered negative comments, with 30.7% ($n=8$) of families in the control group and 34.6% ($n=9$) in the intervention group providing positive comments. In contrast, 30.7% ($n=8$) of family members in the control group and 26.9% ($n=7$) in the intervention group provided negative comments.

The positive comments offered by the intervention group and control groups were mainly around the care and compassion shown by the ICU staff, the care provided, and appreciation for unrestrictive visiting. Negative comments were provided by both groups, and were mainly focused on the frequency of

communication, the limited visibility of medical staff, and the ICU waiting room and ICU entry system. One family member in the control group suggested that “it would be good to have a scheduled brief meeting once or twice a week with doctors in charge of my dad’s care to help update on their care”.

In summary, this chapter has reported results of the two research questions and the three free-text questions which were introduced on the FS-ICU questionnaire. Following the intervention, the experimental group reported lower state anxiety and uncertainty scores, but these failed to reach a level of significance. Both groups of family members were satisfied and happy overall with the care they received in the ICU, but less so with the information and decision-making support offered. Frequency of communication with medical staff and the physical ICU environment were identified as areas that may potentially contribute to family dissatisfaction with their experience in the ICU. A discussion of the results presented in this chapter now follows.

Table 10: Family members' comments about ICU experience

Themes	Positive Comments		Negative Comments	
	Control group (n=8)	Intervention group (n=9)	Control group (n=8)	Intervention group (n=7)
Communication	<p>I was kept informed</p> <p>The information booklet in the waiting room was good</p>	<p>I had good, clear simple facts</p> <p>Always happy to answer questions</p> <p>I was updated when we asked them to</p> <p>I felt well informed</p>	<p>Doctors communicated amongst themselves</p> <p>Frequency of doctors communicating with us could have been better</p> <p>It would be good to have a scheduled brief meeting once or twice a week with doctors in charge of my parents care to help update on their care</p> <p>The care my relative received was very good, but often no sign of a doctor</p>	<p>I had a long wait for information on initial admission</p> <p>Was not included in decisions relating to his care</p> <p>Didn't always see the same doctor</p>
ICU Staff	<p>Compassionate ICU team</p> <p>All medical and nursing staff were easy to talk to</p>	<p>Staff put me at ease and supported me emotionally</p> <p>Staff caring and compassionate</p>	<p>I seen too many different nurses</p> <p>The unit too busy at times</p>	<p>Doctors can be abrupt at times</p>
Care delivery	<p>Completely satisfied with care provided</p> <p>Outstanding care</p>	<p>Excellent care by relative received</p> <p>Level of care was exceptional</p>	<p>No negatives were expressed</p>	<p>No negatives were expressed</p>
ICU environment	<p>Was able to see my relative when it suited me</p> <p>Visiting wasn't restricted which helped</p>	<p>Flexible visiting was the best experience</p>	<p>External waiting room not comfortable</p> <p>Waiting too long at the door when waiting to visit</p>	<p>Waiting too long to gain entry</p> <p>Waiting to visit if ICU busy</p> <p>Waiting room had poor facilities</p>

CHAPTER 6: DISCUSSION

6.1: Introduction

This chapter will discuss the key findings and their contribution to the existing literature, as discussed in Chapter 2. The strengths and limitations of the study will be presented, and the implications for clinical practice and future research will also be proposed.

Family members of the critically ill are suddenly faced with a complex and unexpected situation that is unfamiliar, unpredictable, and stressful. For the past twenty years, it has been established that the need for information, assurance and proximity in the ICU is considered by families to be of paramount importance. Families want information to be provided regularly, to be accurate and honest with regard to the condition of their relative, and provided at a pace that ensures comprehension (Bond et al. 2003, Takman and Severinsson 2006, Fry and Warren 2007, Keenan and Joseph 2010).

Professional guidelines have emphasised the concept of family-centred care as an approach to compassionately and effectively supporting ICU families through stressful and life-changing experiences (Davidson et al. 2017). Through this approach, strategies to improving partnerships with families and evaluating communication interventions between family and ICU staff have been identified as one of the five key priorities (Davidson et al. 2017). The Nelson et al. (2009) toolkit, comprising three specific tools as a means to improve family communication by standardizing the implementation and documentation of a family meeting, was developed using previous research and expert panel opinion. The tools had not been formally tested in the clinical environment. The

aim of this study was to evaluate for the first time the effects of delivering this structured communication strategy versus usual care on levels of anxiety (state and trait), uncertainty, and satisfaction overall and with care and decision-making in families of ICU survivors.

This study provides further evidence that admission of a close relative to the ICU is a stressful event that causes high levels of distress, both acutely and throughout the ICU stay. High levels of anxiety symptoms and moderate levels of uncertainty were recorded in the control and intervention groups of family members when entering the ICU environment. The structured communication tools to support the conduct of a family meeting did not significantly modify the emotional distress they faced upon discharge from ICU. That is, the control and intervention groups had similar levels of anxiety on discharge from the ICU. Whilst a statistically significant reduction in uncertainty could not be found, there was an improvement seen, but only in family members in the intervention group at the point of ICU discharge.

There were no significant intervention effects on family satisfaction, with family members in both groups highly satisfied overall and with the care that they and their relative received on ICU admission and on discharge from ICU. These results offer reassurance of the high-quality care provided by the nursing and medical team within the study site ICU. The results do, however, present opportunities to address the slightly lower satisfaction scores reported for information provided and decision-making.

6.2: Changes in anxiety, uncertainty and family satisfaction in ICU families

6.2.1: State and Trait Anxiety

Anxiety in this study's sample was considerably higher than in working adults in normative data. For perspective, normative state anxiety scores, published in the STAI manual, report that state anxiety scores in working adults are 35.9, which is in the no- or low-anxiety range (20–37) (Spielberger et al. 1983). On admission to ICU, family members in the control and intervention group who were of similar age, and relatives of patients with comparable illness severity and ICU length of stay, experienced state anxiety scores within the high anxiety range (45–80) (median 51.5 versus 51.0) (Spielberger et al. 1983). Following a median length of stay of between 17 to 19 days, state anxiety at ICU discharge did not significantly reduce and remained within the high range for both groups (median 47 control group versus 49 intervention group). In earlier studies, a cut-off anxiety score of 39–40 has been suggested to detect clinically significant state anxiety symptoms (Knight et al. 1983, Addolorato et al. 1999). Family members in this study could be considered as being clinically anxious throughout their ICU experience.

High state anxiety using the STAI have been found in previous studies describing family members in the ICU (Delva et al. 2002, Paparrigopoulos et al. 2006, Chien et al. 2006). Irrespective of the self-report questionnaire used, for example, the Hospital Anxiety and Depression Scale (HADS) or Becks Anxiety Inventory (BAI), anxiety symptoms in relatives of ICU patients are consistently documented to be in the high to very high range (Pochard et al. 2001, 2005, Young et al. 2005, Lautrette et al. 2007, Day et al. 2013, Garrouste-Orgeas et al. 2016, White et al. 2018).

The only study to report state moderate anxiety (38–44) prior to ICU discharge and low anxiety (20–37) symptoms following ICU discharge was conducted by Mitchell and Courtney (2004). One likely factor for consideration to explain this finding, however, was the high proportion of scheduled rather than unscheduled admissions in their study's sample compared to in this study site. Research suggests that family members of expected admissions to ICU experience less anxiety than unexpected admissions (Auerbach et al. 2005, Young et al. 2005, Wong et al. 2017). Less anxiety may well be related to the well-defined processes of sharing information with these family members, both verbally and in writing, pre- and post-operatively and, therefore, they have more predictability of ICU and hospital events (Young et al. 2005).

Trait anxiety scores found in this study were in the high range on ICU admission for the control (median 46) and in the moderate range for the intervention group family members (median 44). Trait anxiety scores remained relatively constant through to ICU discharge. Trait anxiety was higher than normative data published in the STAI manual for working adults of 34.8, which again is in the no or low anxiety range (20–37) (Spielberger et al. 1983).

The level of trait anxiety reported here is comparable with that reported by Paparrigopoulos et al. (2006) (median 44.5) and Jones et al. (2004) (median 47), when measured in family members, either on their family member's ICU admission or one week after their family member's admission to the ICU.

6.2.2: Uncertainty in illness

This is the second intervention study to measure uncertainty in illness in family members of patients admitted to the ICU. The level of uncertainty in illness in

family members regarding their relative's critical illness on ICU admission was 76.5 points (control) and 80.0 points (intervention). Mitchell and Courtney (2004) recorded similar results of 77.2 points (control) and 78.9 points (intervention). These scores are representative of medium levels of uncertainty in illness, ranging from 59–87 points (Mishel 1981). At discharge from ICU and after a prolonged ICU stay (17–19 days), there were differences found between the intervention and control groups' levels of uncertainty. The control group's level of uncertainty was akin to their admission score at 75.0 points, whereas the intervention group, although not reaching a level of statistical significance, demonstrated a reduction in uncertainty of 8.4 points to 67.5 points. A statistically significant reduction in uncertainty in families was demonstrated after transfer from ICU to ward-based care in Mitchell and Courtney's (2004) study, who provided family members with details of what to expect following transfer. These results will be explored further within Mishel's model of "Uncertainty in Illness" (1988) in **Chapter 7**.

6.2.3: Levels of family satisfaction, overall, and with care and information/decision-making

The first two satisfaction summary scores relating to family satisfaction, overall, and with the care their relative received on admission to ICU, indicated that the family members were highly satisfied with the care and treatment of both themselves and their relative. For the degree of satisfaction in the third sub-domain of satisfaction with information and decision-making, the combined score of family satisfaction with information (six questions) and satisfaction with inclusion and support in the decision-making process (four questions) was somewhat lower. Family satisfaction was in the "good" or "mostly" satisfied rather

than the “very good” or “highly” satisfied range at the time of ICU admission (70.2 control versus 72.6 intervention).

In comparing these study site results to the recently published and only UK multicentre ICU family satisfaction study, for overall satisfaction and satisfaction with care on admission to ICU, Ferrando et al. (2019) reported slightly lower results, but these remained within the “very good” range (80 points overall, 83 points with care). In contrast, satisfaction with information and decision-making was at an almost identical level, within the “good” or “mostly” satisfied range (73 points) (Ferrando et al. 2019). International single and multicentre studies demonstrate comparable findings (in Canada, Heyland et al. 2001, 2002, Hendrich et al. 2011; in the USA, Hwang et al. 2014, Clark et al. 2016; in Greece, Gerasimou et al. 2013; in Sweden, Karlsson et al. 2011; in Germany, Schwarzkopf et al. 2013; and in Norway, Frivold et al. 2016, and Haave et al. 2021).

One possible explanation for lower satisfaction in this sub-domain, specifically relating to this study site ICU, is when meeting and speaking with families for the first time, they are updated either during a private meeting or at the bedside by the attending ICU clinician and the beside ICU nurse. They are informed about the current clinical situation, the clinical priorities, and the immediate management plan at the earliest opportunity. They are fully informed of the clinical decisions that are being made rather than being actively included to participate in decision-making around their relative’s clinical care.

The initial efforts of medical staff in the ICU in the study setting, however, include the medical care and stabilisation of the family member’s relative, as well as

numerous other critically ill patients within the ICU (Molter 1979, Bijttebeir et al. 2001, Davidson 2009, Day et al. 2013). Similarly, nursing staff focus on meeting the immediate nursing needs of their patient where they concentrate their efforts on establishing physiological stability (Chien et al. 2006). Attending to family immediately may not be possible, and there can often be an unintentional delay in updating them. In these circumstances, it is entirely understandable that waiting for information is hard to cope with, giving rise to lowered satisfaction if the ICU medical and nursing team are unable to speak with families or involve them at a time which is important to them. In spite of this, family members in this study were happy that they had been given enough time for having their questions answered and with the willingness of the ICU staff to address their concerns.

When the opportunity arises to update families, it is known that the emotional distress brought about by their relative's unexpected critical illness, coupled with their wait for information, can interfere with their cognitive processes (Mishel 1988). This can lead to differences in their ability to understand, remember and keep track of complex information about their family member's clinical condition (Pochard et al. 2001, Azoulay et al. 2005). Their perceptions of a lack of information initially may therefore be because they did not fully understand or remember the information that they had received from the ICU medical and nursing staff. For these reasons, lower family satisfaction with information and inclusion and support with decision-making at the onset of their relative's critical illness was not an unusual finding.

6.3: Impact of the intervention on anxiety, uncertainty and family satisfaction

6.3.1: Anxiety

The structured communication strategy did not specifically have an effect on self-reported state anxiety symptoms in families of ICU survivors at discharge from the ICU. The intervention group did record a decrease, but this did not reach a level of significance, nor was it exclusive to this group. Family members in both groups remained within the classification range of high-level state anxiety. These findings are consistent with four other intervention studies, where the delivery of written information around ICU recovery, ICU transfer, coping skills training, or family support were unsuccessful in alleviating anxiety (Jones et al. 2004, Mitchell and Courtney 2004, Cox et al. 2018, White et al. 2018). Three studies did report a favourable change in anxiety post-intervention, using either the STAI or HADS; however, although they did demonstrate a significant decrease, it is important to note that anxiety symptoms continued in the high range (Chien et al. 2006, Lautrette et al. 2007, Garrouste-Orgeas et al. 2016).

There are several possible explanations as to why the structured communication strategy in this study did not have an impact on state anxiety symptoms. For example, state anxiety reflects an individual's psychological and physiological response to a specific situation that is perceived as threatening or dangerous (Spielberger et al. 1983). In addition, it is frequently reported in the literature that family members experience high anxiety because their relative is admitted to the ICU suddenly and unexpectedly, often in a critical and physiologically unstable condition, and the majority have no previous exposure to the highly technical unfamiliar ICU environment (Jamerson et al. 1996, Mishel 1988, Bijttebeir et al.

2001, Delva et al. 2002, Lam and Beaulieu 2004, Ågård and Harder 2007, Johnson et al. 2019).

In this study, anxiety was re-assessed on ICU discharge and after an average length of stay of between 17 and 19 days. Families often feel a sense of security with prolonged exposure to the ICU environment, as they become more familiar with the routine and the increased nurse-to-patient ratio, whilst simultaneously developing a close and trusting relationship with the ICU nursing and medical team (Lam and Beaulieu 2004, Mitchell et al. 2009). The anxiety they were experiencing could in part be explained in relation to the enormity of change they were facing, as they were about to move to an unfamiliar ward, with unfamiliar nursing and medical staff, with a reduced level of nursing support and with an uncertain outcome.

Although discharge from ICU is seen as a positive step in terms of the patient's physical recovery, symptoms of anxiety continue to be elevated in family members (albeit at a reduced level) prior to the patient's transition of care. This is not surprising because, even at the point of ICU discharge, critical illness would not have entirely diminished. It will simply be showing a positive improvement in their relative's physiology to warrant the transition from ICU to ward-based care.

The existence of a higher predisposition (trait) to be anxious in both groups on admission to ICU would also elicit the higher state anxiety response. According to Spielberger et al. (1983), individuals with high trait anxiety respond to situations as if they were threatened with greater intensity than those with low trait anxiety. Thus, a family member who is prone to be anxious should experience more anxiety. The results reported here provide additional support

for the connection between the two concepts of state and trait anxiety. Family members in this study who are prone to anxiety, as reflected in their high trait score, were also highly anxious when faced with the situation of having their relative either admitted to or discharged from ICU.

It has also been suggested that trait anxiety should not be the sole measure of a predisposition to state anxiety, but, instead, it is equally a risk factor to emotional disorders and sleep disturbances (Grupe and Nitschke 2013, Nordahi et al. 2019, Weeks et al. 2019). High levels of depressive symptoms, as well as PTSD, are reported in ICU family members and are included in the PICS-F cluster of psychological disorders they experience (Pochard et al. 2001, 2005, Rodriguez and San Gregorio 2005, Young et al. 2005, Paparrigopoulos et al. 2006, Needham et al. 2012). Both state and trait anxiety levels equivalent to the levels observed in both groups in this study have been shown to specifically increase the risk for family members developing PTSD.

Paparrigopoulos et al. (2006) found that high state and trait anxiety symptoms increased the risk of PTSD symptoms in ICU family members at six months after their relative's discharge from hospital. Their relative's illness severity or age of the family member did not increase this risk. Jones et al. (2004) found that family members residing in the UK, with high trait anxiety levels, failed to show that the provision of general written information around recovery after ICU reduced state anxiety at eight weeks and six months after ICU discharge. There was also an association found between early anxiety and symptoms of PTSD in relatives at their six-month follow-up. The potential harmful effects of anxiety could therefore

have an impact on the ability of family members to provide for their relative's healthcare needs after discharge from ICU and hospital.

6.3.2: Uncertainty in illness

At the point of their relative's transition of care from ICU to ward-based care, there was a reduction in uncertainty levels seen in those family members who received the structured communication intervention, although these did not reach a level of statistical significance. Mitchell and Courtney (2004) did report a statistically significant reduction in levels of uncertainty in ICU family members, when measured after ICU discharge. Their study included a larger convenience sample, which could suggest that the smaller convenience sample in this study may not have had sufficient power to detect a significant difference in uncertainty. The post hoc power calculation, however, indicated that the study was sufficiently powered to detect a difference. It is more plausible that, because family members were given specific details on what to expect when their relative moved to the ward, doing so helped reduce their uncertainties to a much lower level.

A moderate level of uncertainty and high level of anxiety experienced by both cohorts of ICU family members was not an unanticipated finding. The overwhelming anxiety associated with uncertainty experienced by family members is well documented (Jamerson et al. 2006, Ågård and Harder 2007, Lam and Beaulieu 2004, Iverson et al. 2014, Wong et al. 2017). This is because a critical illness episode exposes families to a relatively uncertain trajectory; they frequently experience periods of physiological instability in their relative's clinical condition, and it is not always clear whether their relative will survive, or whether they will suffer permanent physical disability (Johansson et al. 2005). Every day,

family members in both the control and intervention groups, whose relative was a patient in the ICU, were being faced with an uncertain situation that they were trying to make sense of (Ågård and Harder 2007).

Family members speak openly of the uncertainty they feel when their relative is critically unwell and when faced with the possibility of losing them, elevating their levels of anxiety (Burr 1998, Delva et al. 2002, Ågård and Harder 2007, Mitchell and Courtney 2004). These feelings of anxiety and uncertainty are “increased by stressful circumstances inherent to intensive care units” (Delva et al. 2002, p. 22). These stressful circumstances are specific to the ICU environment because this clinical area consists of highly specialised and technological equipment, noisy medical device alarms, and involves the constant monitoring of their relative’s clinical condition (Delva et al. 2002).

The findings in this study propose that admission to ICU and the transition to ward-based care are clinical milestones which produce anxiety and uncertainties in family members of ICU patients who survive. Whilst there was a reduction in anxiety, it was not exclusive to the intervention group and remained high throughout the family’s ICU journey. Uncertainty levels, however, showed a noticeable but non-significant decrease exclusively in those families who received the intervention compared to those receiving usual care. As highlighted previously, these results will be explored within Mishel’s model of “Uncertainty in Illness” (1988) in **Chapter 7**.

6.3.3: The impact of the communication strategy on family satisfaction, overall, and with care

The implementation of the communication tools did not significantly affect family members’ satisfaction scores overall or with care. Family members in the control

and intervention groups were extremely satisfied overall and with the quality of care received. At the point of ICU discharge, and following the intervention delivered by the ICU medical and nursing team, family satisfaction scores showed continual improvement but did so in both groups and did not reach a level of significance. A plausible explanation for this may be because there was minimal room for improvement, given the high pre-intervention satisfaction scores. These high pre-intervention satisfaction scores would be less sensitive to any further quality improvement efforts.

The higher degree of satisfaction with how they and their relative were being cared for can, in part, be explained by the open and flexible visiting policy, which has been operational within this ICU for many years. All family members visiting the ICU have the opportunity to spend increased quality time at the bedside with their relatives. They are encouraged and supported by the ICU nursing team to participate in their relative's care should they wish to do so. As part of the admission process already established within this study site, ICU nursing staff provide all family members with a printed information leaflet explaining how they can actively contribute to the care of their relative. Enabling families to have flexible access and providing them with the opportunity to assist nursing staff to provide direct care to their relative facilitates the meeting of two of the three most important family needs of critically ill patients, that of proximity and assurance (Leung et al. 2000, Bijttebeir et al. 2001, Auerbach et al. 2005, Omari 2009, Kinrade et al. 2010, Hinkle and Fitzgerald 2011, Ozbayir et al. 2014).

Allowing family members to remain in close proximity to their relative, with the possibility of participating in their care, as previously discussed, could have

accounted for the high level of family satisfaction. Maintaining this closeness enables families to become more familiar, relaxed and reassured in the ICU environment, with the daily routine, and with the ICU nursing staff (Lam and Beaulieu 2004, Mitchell et al. 2009). Mitchell et al. (2009) revealed that family members who were invited to participate in the fundamental care of their relative perceived an increase in respect, collaboration, and overall family satisfaction compared to family members who were not invited to participate in the delivery of care.

6.3.4: Evaluation of the communication strategy on satisfaction with the decision-making process

The third satisfaction summary score, satisfaction with decision-making, showed lower satisfaction scores. Family members who experienced the structured communication intervention to aid with the conduct of family meetings delivered by the ICU medical and nursing team experienced similar levels of satisfaction to those who did not receive the intervention.

This study suggests that the standardised communication strategy, inclusive of the three communication tools, had no effect on this sub-domain of family satisfaction. In fact, a further reduction in satisfaction was observed at ICU discharge. This was a surprising finding, as having time set aside for regular family meetings has been recommended as an approach for ensuring that families are given accurate and clear information, are listened to, and have an opportunity to have questions answered and feel supported (Gay et al. 2009, Nelson et al. 2009).

The majority of family members in the intervention group and half of family members in the control group had never visited the ICU previously, and

understandably were experiencing high levels of anxiety and uncertainty when their relative was admitted to the ICU. Family members, especially those with no past experience of ICU, are found to have falsely optimistic and unrealistic expectations for their relative's treatment and care, where a failure to meet these expectations is known to heighten anxiety (Pochard et al. 2001, Azoulay et al. 2005). The uncertainty of the situation, coupled with anxiety and expectations that are not feasible or realistic, also affect perceptions of satisfaction (Mishel 1988, Azoulay et al. 2005, 2016). Family members in this study may have higher expectations of their relative's ICU care and treatment, thereby lowering satisfaction levels.

Throughout the course of their ICU stay, the family members continued to feel overwhelmed with anxiety and uncertainty, which influences the way in which even the most basic information delivered is understood and processed, and clouds their decision-making ability (Mishel 1988, Pochard et al. 2001, Azoulay et al. 2005, Johnson et al. 2019). Even if adequate information was provided by the ICU medical and nursing team, family members' perceptions of a lack of information may be because they did not understand or had not received the information they wanted, resulting in dissatisfaction. Furthermore, as Rothen et al. (2010) pointed out, it would be impossible and unrealistic to expect that every family member is completely satisfied with all the situations they experience in the ICU.

Family dissatisfaction at the point of discharge may also simply be because the ICU medical and nursing team spend time communicating directly with the patient at the bedside. Family communication at this point in their relative's recovery is

often required less frequently. The reason for this is that patients themselves are able to request and gain valuable information, participate in decisions regarding their treatment and ongoing care needs, and can convey the information they wish to be shared to their families themselves. This could explain why, at the point of ICU discharge, 80% of the family members in the intervention group and 69% in the control group reported having had inadequate time to have their concerns addressed and questions answered. These findings do imply that all families want to obtain information and have time devoted to share their concerns throughout their entire ICU stay, even when their relative can impart information themselves.

6.4: Family satisfaction in ICU survivors in ICU compared to ICU non-survivors

Levels of satisfaction in the three sub-domains in families of ICU survivors reported here are comparable to those reported by Heyland et al. (2002) and Ferrando et al. (2019). Families of ICU survivors, with a similar illness severity, were highly satisfied overall, and with the care that their relative and themselves received, and were mostly satisfied with information and decision-making.

Previous satisfaction studies involving families of ICU non-survivors, or those with high severity of illness, are reported to be more satisfied with their ICU experience and inclusion and support with the decision-making processes than ICU survivors (Wall et al. 2007, Stricker et al. 2009, Frivold et al. 2016, Ferrando et al. 2019, Haave et al. 2021).

This study was not powered to detect such an association, as families of patients who were transferred to palliative care, or who died, were not asked to complete

the FS-ICU. However, these results show that family satisfaction overall and with care was higher, whereas satisfaction with decision-making was lower when compared to family satisfaction studies in ICU non-survivors. These results demonstrate that the ICU nursing and medical team dedicate as much time delivering high-quality care to patients and families of ICU survivors and non-survivors during their ICU stay. They could, however, provide additional evidence that there is a more sustained focus on providing these families with information and inclusion and support in decision-making when their relative is dying in the ICU.

6.5: Comments reported by ICU family members

It has been suggested that some determinants of family satisfaction cannot be quantitatively assessed, and the FS-ICU provides only a partial picture (Hendrich et al. 2011, Schwarzkopf et al. 2013). The FS-ICU questionnaire's three free-text questions allowed the family members in this study to document areas which they felt the ICU study site were doing well and those areas where improvements could be made.

In the free-text responses, which were organized by communication, ICU staff, care delivery, and ICU environment, positive comments were more frequently expressed in both the control and intervention group for aspects of care, caring and compassionate staff, and flexible visiting arrangements. Family members in the intervention and control group expressed that they were confident and satisfied with the ICU staff's ability to deliver compassionate care to their relative. They stated that "excellent care" was evident and that the "level of care was

exceptional". These comments support the quantitative findings that the care delivered was very good in both groups.

Negative comments were expressed more often by family members in both the intervention and control groups for frequency of communication with medical staff. One family member in the control group specifically expressed that the "frequency of doctors communicating with us could have been better", another said "It would be good to have a scheduled brief meeting once or twice a week with doctors in charge of my parents care to help update on their care", whilst another wrote that "there was often no sign of a doctor". In the intervention group, the participants explained that there was a "Long wait for information on initial admission".

Negative comments were also made about the ICU waiting room and entry system, which suggests that improvements were needed. Similar findings of dissatisfaction with the frequency of communication and the ICU environment have been consistently reported (Heyland et al. 2002, Karlsson et al. 2011, Hendrich et al. 2011, Schwarzkopf et al. 2013, Hwang et al. 2014, Clark et al. 2016).

6.6: Barriers to family meetings

Two factors were seen to negatively impact on the delivery and effectiveness of the structured communication intervention in this study: 1) the availability and workload of medical and nursing staff, and 2) the timing of the family meetings.

6.6.1: Availability and workload of medical and nursing staff

At the time of undertaking this study, the ICU consisted of 19 beds and was medically staffed by two intensivists during the week, one intensivist at the weekend, and one night consultant anaesthetist, supported by specialist trainees and foundation doctors. The research nurse who coordinated the planning of the meetings was required to make multiple telephone calls to family members to agree a mutually acceptable date and time for the family meeting to be undertaken within the ICU. This often required planning several days ahead to allow the family member to schedule time away from work and when the ICU clinician could be present.

Alongside the practical challenges of pre-arranging a family meeting, triaging resources within the study site on the day to ensure medical and nursing staff presence at the meetings was difficult at times. The illness severity and complexity of the patient and/or numerous other critically ill patients within the ICU on occasions was too high for the ICU medical and nursing staff to spend sufficient time with the family members during the meeting.

At ICU admission, the medical and nursing staff members spend time updating families, predominantly at the bedside, as their relative's critical illness is often complex and serious. Updating families in this way on admission would explain why family members in both groups reported that they had adequate time for their questions and concerns to be answered. At discharge, less time is often afforded to them and is directed more towards the patient themselves. The results of this study suggest that families, throughout their ICU episode, want the same time

allocated to them to speak to and be listened to by the medical and nursing teams.

6.6.2: Timing of the family meetings

The standardised family meetings were scheduled to be held up to 72 hours after their relative's ICU admission and weekly thereafter until their relative's transfer to ward-based care. The results of this study suggest that the timing of the first family meeting may have been too late, contributing to less frequent communication with families, and thereby resulting in lower satisfaction and no significant reductions in anxiety or uncertainty.

In the study by Laurette et al. (2007), family members had received three formal family meetings within the first 48 hours of their relative's admission to ICU, the first of which was held within 12 hours of their admission. Their intervention with the opportunity for more talking and listening time for family members reduced PTSD, anxiety and depression at 90 days. Chien et al. (2006) reported increased satisfaction, particularly satisfaction with information by executing a needs-based training programme within 24 hours of the family member's relative's admission, and included daily telephone updates by the bedside nurse. Hwang et al. (2014) found that families who participated in more than three formal family meetings within a 3–5-day period were more likely to be completely satisfied with the frequency of communication. Furthermore, White et al.'s (2018) delivery of a family support intervention, inclusive of a family meeting at day one, showed that, whilst they did not show a reduction in psychological burden over time, family members' rating of the quality of communication did significantly improve.

The practical difficulties of arranging and attending formal family meetings and the timing of the family meeting may have contributed to the ineffectiveness of this intervention. It can at times be difficult for nursing and medical staff to realistically fulfil and meet the expectations of family members whilst also being responsible for numerous critically ill patients or those with high illness severity. Family members expressed the need to speak with the ICU team more often than they were able to, and the delivery of the intervention may have been held too late and too infrequently to significantly affect the outcome variables.

Providing family members with printed information and delivering formal routinely scheduled family meetings with medical and nursing staff, away from the bedside, did not significantly reduce their anxieties and uncertainties. However, uncertainty in illness did show a reduction, and this can be readily linked to Mishel's Uncertainty in Illness Theory (Mishel 1988).

CHAPTER 7: INTERPRETATION OF THE RESULTS THROUGH MISHEL'S MODEL OF PERCEIVED UNCERTAINTY IN ILLNESS

7.1: Overview of the model

The concept of uncertainty was first proposed by nurse theorist Merle Mishel (1988) and defined as a cognitive state arising from the inability to determine meaning or the inability to predict disease-related events. According to Mishel's theory, uncertainty is a combination of doubt, indecision, ambiguity and perplexity in an individual, and arises when they are in a critical, sudden, unexpected, and/or life-threatening situations and unable to predict future events.

The theoretical framework proposed by Mishel (1988) has four main components: 1) antecedents of the uncertainty, 2) appraisal of the uncertainty, 3) coping strategies dependent on the appraisal outcome, and 4) the level of adaptation associated with effective coping (**Figure 15**).

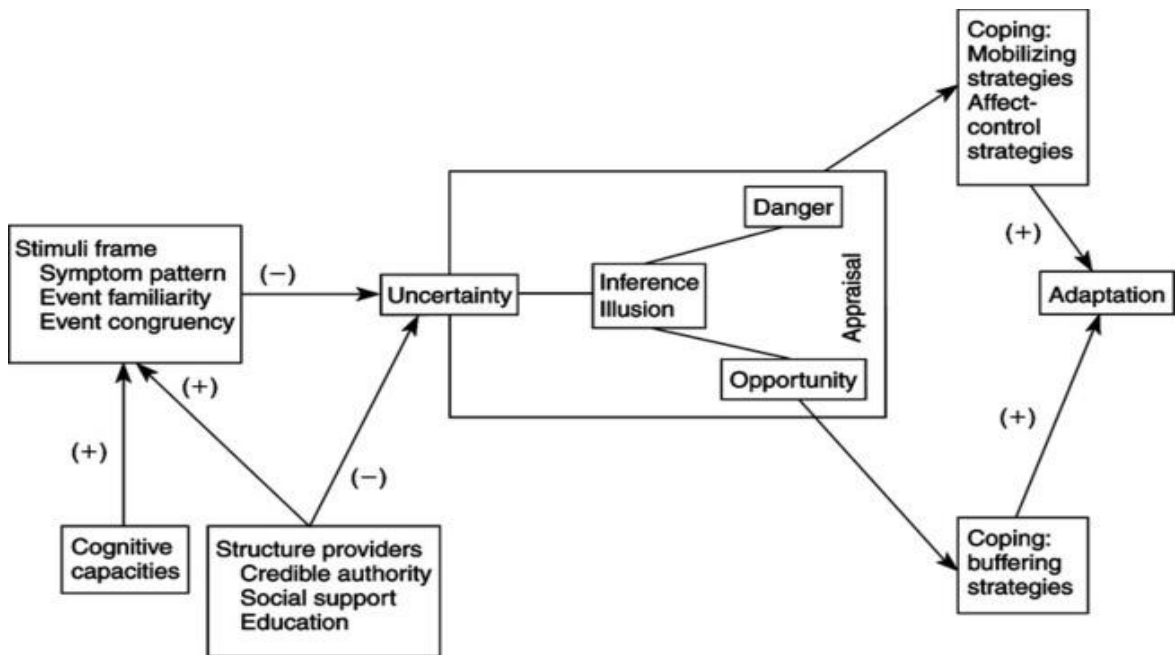


Figure 16: Model of Uncertainty in Illness (Mishel 1988) (Image: *The Journal of Nursing Scholarship*, 20 (4), p. 226)

The three antecedents that precede a person's uncertainty about the illness and represents how information is offered and processed by the individual are described as stimulus frame, cognitive capacity, and structure providers (Mishel 1988). Each of these factors positively or negatively affects the uncertainty perceived by individuals. **Stimulus frame** has three elements; namely, symptom pattern, event familiarity, and event congruence, which are used by individuals to reduce uncertainty. **Symptom pattern** refers to the extent to which symptoms exist with enough consistency and reliability (Mishel 1988). **Event familiarity** refers to the degree to which a situation is habitual and/or contains familiar cues (Mishel 1988). **Event congruence** explains the coherence between illness-related real situations and expectations. If there is a difference between what the person expects and what they actually experience, then this leads to stress and uncertainty because they no longer know what the future will bring (Mishel 1988).

Stimulus frame can be influenced by two variables: cognitive capacity, and structure providers, both of which assist individuals to process the information they receive and directly and/or indirectly help them to appraise and structure meaning to the stimulus frame.

Cognitive capacity is defined as an individual's informational processing ability (Mishel 1988). As previously discussed, information processing can be impaired during an acute illness episode because of the unfamiliar technical, environmental, physical, or psychological factors, such as fatigue, anxiety, and stress (Mishel 1988, Pochard et al. 2001, Azoulay et al. 2005, Day et al. 2013).

Structure providers refer to the "resources available to assist the individuals with the interpretation of the stimulus frame" and consist of their social support,

credible authority and education level (Mishel 1988, p. 225). Social support received from family and friends, or those with a similar experience, helps the individual to understand the clinical environment and increases the “event congruency”. Credible authority refers to the degree of trust and confidence that individuals have in the healthcare provider’s ability to make a diagnosis, control the symptoms, and provide adequate information around their relative’s illness (Mishel 1988). According to Mishel (1988), “the relationship with the healthcare provider has been reported as the major means for the prevention of uncertainty” (p. 228).

Alongside the structure providers of social support and credible authority, the level of education represents a person’s knowledge base and helps in the interpretation of the stimulus frame (Mishel 1988). Overall, structure providers represent important resources that can directly and indirectly assist individuals to appraise and structure meaning to an illness-related event and therefore influence the extent of their uncertainty.

Uncertainty is a neutral experience until a person is presented with an acute illness and appraisal occurs (Mishel 1999). When individuals experience feelings of uncertainty, they appraise the situation as either a threat or opportunity, and engage in a process to adapt to the uncertainty (Mishel 1988). If the individual appraises uncertainty as a threat or danger, they will attempt to enact coping strategies, such as vigilance and information-seeking, to reduce the uncertainty they are facing (Mishel 1988). Based on Mishel’s theory, if these coping strategies are effective, successful adaptation will occur, helping the individual to reduce uncertainty and manage negative emotions such as anxiety.

Mishel's theory has been extensively applied to explore adult and child patients who have been diagnosed with cancer, with caregivers, and with parents of hospitalised children (Mishel 1983, Christaman 1990, Mishel et al. 1991, Bailey et al. 2007, Harkness et al. 2014, Byun et al. 2016). There is limited qualitative research which broadens current understanding of uncertainty in critical illness (Jamerson et al. 1996, Burr 1998, Johansson et al. 2005, Ågård and Harder 2007, Wong et al. 2017). Only one previous quantitative study has examined the effects of delivering information prior to ICU transfer on uncertainty and anxiety (Mitchell and Courtney 2004). The following section will build on this work and provide an explanation of the results of this study within the theoretical framework of uncertainty in illness in family members of the critically ill at the onset and end of their ICU journey.

7.2: Mishel's theory of Uncertainty in Illness in relation to family members of the critically ill

In this study, it was uncommon for family members to have had any previous exposure to ICU, and their relative's admission was unexpected. The sudden and unexpected admission of a relative to the ICU would be a direct source of uncertainty and exacerbated anxiety for these family members. This is primarily because, at the onset of critical illness, the family member would not be able to assign definite values to the event and/or anticipate outcomes because of the foreign nature of the environment and the inability to initially make meaning of the critical illness experience (Mishel 1997). Anxiety and the unexpected nature of an ICU admission was found in Mitchell and Courtney's (2004) study to be significantly related to uncertainty.

Uncertainty and anxiety, seen at the time of ICU admission for both the control and intervention group family members, was entirely predictable and supports the conceptualisation of uncertainty. The unpredictability and often life-threatening nature of their relative's critical illness symptoms firstly prevents family members from forming a symptom pattern about their relative's critical illness status (Mishel 1988). Secondly, the lack of event familiarity to mitigate against this develops through past experience of the clinical environment and is acquired over time (Mishel 1988). The majority of family members in this study had never visited the ICU previously. Thirdly, event congruency explains the coherence between illness-related real situations and expectations. Family members entering the ICU for the first time have limited knowledge about the critical illness, medical treatment and ICU technical equipment/environment, which can give rise to unrealistic expectations, which in turn is known not only to cause uncertainty and anxiety, but also affects their satisfaction (Mishel 1988, Pochard et al. 2001, Azoulay et al. 2005, 2016, Wong et al. 2017, Haave et al. 2021). The unintentional wait for information that the family members need from the ICU staff intensifies feelings of anxiety and uncertainty, to the extent that it adversely affects their cognitive processing (Mishel 1988, Azoulay et al. 2005, 2016).

Mishel recognised that, throughout the acute illness period, there will always be a component of uncertainty for family members because of daily fluctuations in their relative's condition (Mishel 1990). The results of this study confirm that family members were uncertain, not only at the onset of their relative's critical illness, but also at the point of transfer to ward-based care. However, a clear

decrease was seen solely in those who received the structured communication intervention.

Less uncertainty observed in those receiving the intervention prior to ICU discharge in family members could have been because of better event familiarity. Unfamiliarity of the ICU environment and routine would initially be a direct source of uncertainty and anxiety. The study site ICU operated an open visiting policy, thus they had increased opportunity to learn more about the technical environment, become more familiar with the ICU staff and with the routine, resulting in less uncertainty. They were also able to be involved in their relative's care, observe the actions of the ICU medical and nursing teams, and engage directly with the nursing staff at the bedside. In addition, the nurse-to-patient ratio is higher in the ICU environment than general wards and greater attention and care are provided to them. However, increased event familiarity cannot be the sole reason for the reduction in uncertainty in the intervention group, as the control group, who were afforded the same visiting opportunities, time at the bedside, and nursing support, did not show a similar reduction.

According to Mishel (1988), information-seeking is a coping strategy enacted by individuals to lessen their uncertainty. She noted that a lack of information by a credible source is a key contributor to the appraisal of uncertainty. Family members who received the intervention were less uncertain, as information was delivered by medical and nursing staff who served as structure providers. Based on her theory, this reduction occurred because factual and specific information about the patient's condition and treatment were delivered, not only at the

bedside, but also during the family meeting by credible sources; in this instance, by the bedside ICU nurse and ICU clinician (Mishel 1988).

The formal family meeting, conducted by both medical and nursing staff, provided family members with a broad and structured repertoire of information, expanded their knowledge base, and improved their interpretation of the critical illness. Furthermore, the family meeting guide, offered as part of the intervention, helped family members to assess whether they felt they had been adequately informed about the situation, and whether they understood the information.

Families of patients in the ICU describe the support that they receive from ICU nurses as being crucial in helping them cope with the situation, understand what is happening, and convey a sense of security (Engström and Söderberg 2004). Involving nurses as well as medical staff in this study to participate in the family meeting would have facilitated better communication at the bedside. Family members can perceive information from medical staff as being more complete than information solely received from the ICU nurses, but they often find it difficult to understand (Schwarzkopf 2013). As nurses were present at the meeting, there was no loss of information outwith the family meeting; the nursing staff would have been aware of what information had been shared. Nurses at the bedside as structure providers can continue to help reduce uncertainty directly, by interpreting the evolving critical illness, or indirectly, by providing assistance in the interpretation of the stimulus frame (Mishel 1988).

The findings in this study are supportive of Mishel's (1988) established theory of uncertainty in illness. The complexity and unpredictability at the onset of critical illness was a major part of the uncertainty and anxiety experienced by all family

members in this study. When faced with a critically ill relative, they have to shift rapidly into a world of many unknowns: whether their relative will live or die, ICU staff, ICU environment, equipment, and procedures, and even the language used will be unfamiliar. The uncertainty experienced as a result of the critical illness becomes a significant source of anxiety.

The theory emphasizes that event familiarity and effective communication from credible sources serve as key factors reducing uncertainty in illness. The intervention implemented at this study site provided ICU family members with verbal information, delivered by a dual source, in the form of a formal family meeting. A printed family meeting guide for family members to reflect on their current knowledge in preparation for and during the family meeting was also provided. The results of this study suggest that keeping family members informed about their relative's critical illness and involving them in their care is of benefit in reducing the uncertainty they experienced. Bedside ICU nurses in particular can help families to manage their uncertainty by providing information about their illness, and by offering realistic reassurance to help them develop meaning of their ICU experience, which imparts a sense of security. To conclude, a summary of the key findings and the implications for clinical practice will now be discussed.

CHAPTER 8: CONCLUSION

8.1: Conclusions

This study site ICU specifically implemented a newly standardised set of communication tools to aid the conduct of regular family meetings for family members whose relative survives. The goal of the intervention was to provide a structure to communication processes within the ICU, evaluating their effectiveness by prevalence of anxiety, uncertainty, and family satisfaction scores.

The study confirms that admission of a relative to the ICU is a significant and stressful event. Both the intervention and control group family members, entering the ICU predominantly for the first time, were highly anxious and uncertain. This was because of their relative's sudden and unexpected admission and critical clinical condition, and their unfamiliarity with the highly technical ICU environment. The unintentional wait for any information can further intensify their psychological distress to the extent that it may have an impact on their ability to manage and process incoming information. This can lead to misinterpretation and/or recollection of information provided by the ICU team and dissatisfaction with care.

Providing family members with printed information and delivering formal routine scheduled family meetings with medical and nursing staff, away from the bedside, did not significantly reduce their anxieties and uncertainties. There was, however, evidence to suggest that, compared to ad hoc communication methods, those receiving the structured communication tools were less uncertain at the point of their relative's discharge from ICU. These findings were encouraging and

support the theoretical framework of uncertainty in illness proposed by Mishel (1988). They were explained by increased event familiarity with the environment and ICU routine, and with being provided with structured information about their relative's treatment and condition by dual credible authorities. Meeting the family members' needs would have better prepared them to cope with their relative's ICU stay when compared to those who received ad hoc communication methods.

The results showed that families were very satisfied with a large portion of their ICU stay, but that there was lowered satisfaction with information, and inclusion and support with decision-making. They would have also preferred more time at discharge to express their concerns and obtain answers to their questions. These findings were supported in the literature by the understanding that satisfaction with communication is dependent on each family member's personal expectations, cognitive processes which may lead to differences in how information is understood, uncertainty of their relative's outcome, and the reduced requirement for family communication on discharge.

The inclusion of the data from the three free-text questions allowed the family members an opportunity to share their opinions on any aspect of their ICU experience, and gave further insight into the quantified results. From the examples provided, it was suggested that increased frequency of communication with medical staff and improving the ICU environment may lead to family members being more satisfied. It was recognised that the timing of the family meetings may have been held too late and too infrequent to provide significant benefit to the patient's family.

In conclusion, this study adds new insights about the role for structured communication tools in the ICU and the impact that these have on family members' psychological well-being. Initiating the family meetings earlier and prior to discharge from ICU is more likely to be effective in reducing the psychological impact of their relative's critical illness.

8.2: Strengths and limitations of the research

This study is the first to examine the communication tools developed by Nelson et al. (2009) in the ICU clinical environment, and measured their effectiveness in relation to anxiety, uncertainty, and level of family satisfaction with having their information needs met. More so, the adaptation of the intervention included the family in its design. As a structured set of communication tools, they were found to be simple to use, and I would recommend their ongoing use within the ICU clinical area.

This is only the second intervention study to investigate uncertainty in illness in ICU family members following the communication strategy, reporting similar results to those of Mitchell and Courtney (2004). This study, however, presents new knowledge regarding family members' anxiety and uncertainty, as a high proportion of the patients in their study were elective surgical patients, whereas, in this study, the majority were family members of emergency medical patients. These findings show that, irrespective of the nature of a patient's ICU admission, family members are anxious and uncertain at the onset of their relative's critical condition and as it improves in the ICU.

It was shown that the majority of family members were happy and satisfied with the care and treatment that they and their family member received in the ICU.

Inclusion of the qualitative data from the free-text questions strengthened the quantitative results. In particular, the quantity of communication with medical staff and the physical ICU environment were identified as areas contributing to family dissatisfaction with their experience in the ICU.

All three questionnaires used in this study were well validated and reliability-tested questionnaires that have been translated into several languages and used in many countries. A further strength is therefore that all three questionnaires have good psychometric properties.

Similar to many studies, there were a number of limitations that must be considered when interpreting the results and conclusions from this study. This was a single-centre study, situated in the UK, and the first to test the communication tools within the ICU clinical environment. Whilst the results are informative, they may not reflect the general population of ICU family members, given the differences across countries and cultures. The small sample size and convenience sampling in a single ICU might also limit its generalisation to different ICU settings, as only family members present at the bedside or in the waiting room were recruited. The small sample size may not have provided significant power to detect significant differences. Furthermore, inferences from the small number of free-text comments are likely to represent the opinions of family members in the study site ICU, and may not represent the experiences of all family members.

The enrolment of family members was a difficult process for the research nurse. Two reasons may be proposed for this difficulty: lack of interest of family

members to participate, or the narrow inclusion criteria of only first-degree family members.

In order to minimise the influence of social desirability bias, the questionnaires were distributed by a research nurse who was not part of the ICU clinical team. However, family members submitted their responses when their relatives were still in the ICU and may have felt pressure to respond affirmatively due to fear of retribution. Collecting data specially relating to family satisfaction with care whilst their relative remains an inpatient in the ICU can potentially provide false-positive results. It was emphasised to the family members by the research nurse that the questionnaires were anonymous and that the research nurse did not work within the clinical area. The intervention was deployed as a toolkit with three components: 1) meeting planner, 2) meeting guide, and 3) meeting documentation template. It is not known whether one element of the intervention had a more positive effect than the other, because the outcome was an evaluation of the entire intervention. I did not systematically examine family members' knowledge and understanding of the information presented following the formal family meetings. Such an evaluation might have contributed to a better understanding of the effectiveness and appropriateness of the communication intervention.

8.3: Relevance to clinical practice

The findings of this study have important implications for ICU nurses in clinical practice and further research.

The needs of families in ICU have been the focus of family-related research since the late 1970s. It is universally accepted that families want honest, accurate and

up-to-date information; they want to be close to their relative, and they want to be assured that their relative is being well cared for. ICU nurses are the constant in the family's ICU journey. They are the most visible family resource, who often have the best knowledge of and strongest relationship with the family.

Mishel's Uncertainty in Illness theory provides a theoretical framework for ICU nurses to better understand uncertainty and the intense anxiety that is underpinned by uncertainty that these families face (Mishel 1988). Nurses, as a credible authority, are part of the theory's antecedent structure providers who can help and support families to understand the rationale for treatment, create a familiar environment, raise their knowledge base, and, importantly, assess whether their expectations align with the potential outcomes for their relative.

In recognition of the findings in this study and the significant role that nurses play in ensuring effective communication with families, nurses should be present during all family meetings. Families should be offered regular and structured meetings, especially within the first 24–48 hours of their relative's admission. Furthermore, it is important that both ICU nurses and medical staff recognise the impact of family members' emotional state on information processing to ensure that they accurately interpret and understand the information provided.

The unfamiliarity of the ICU environment was a direct source of uncertainty and anxiety for families in this study site ICU. As part of a quality improvement project, a member of the ICU site nursing team has prepared a new information leaflet given to family members on ICU admission. The nursing staff also proactively explains the information provided on commonly used equipment, daily routine, ICU personnel uniforms, and on how to participate with care.

The two private family rooms have been redecorated and now include reading material and tea- and coffee-making facilities. The two overnight rooms have also been redecorated and include a television, a double sofa bed, a fridge and tea- and coffee-making facilities, whilst the relatives' waiting area outside has been supplied with a soft drinks machine.

Educational opportunities, arising from this research, will, firstly, focus on encouraging clinical practice that reflects the importance of recognising and meeting family needs. Secondly, they highlight the crucial role that nurses have in helping and supporting families to manage their uncertainty and anxiety of the situation. The study site has taken significant steps towards meeting family needs and support in the clinical application of family-centred care by establishing unrestricted visiting arrangements, and by encouraging family presence and active participation during provision of care. Providing nurses with further educational resources to raise the profile of family needs, uncertainty and anxiety will increase their confidence in the early identification and management of these.

8.4: Future Research

The structured communication tools implemented here were simple and easy to use within the clinical environment. Family members need regular updates from the ICU team, especially within the first 24 to 48 hours, and throughout their stay, but this also includes when they are being transferred to ward-based care. Larger-sample quasi-experimental studies are required to continue to test the use of these promising structured communication tools in ICU.

Further research using the Uncertainty in Illness theory is needed to add to this existing body of knowledge regarding how family members process a critical

illness event and evaluate interventions to assist families to deal with the uncertainty. The evidence would suggest that, in doing so, this will enhance ICU nurses' awareness of the psychological difficulties experienced by these family members and will continue to promote improved outcomes for both the patients and their families.

8.5: COVID-19 pandemic

The coronavirus disease 2019 (COVID-19) pandemic has spread throughout the world, causing hospitals to rapidly expand their ICU capacity, and has resulted in the disruption of the most integral aspect of care in most ICUs: family visitation. The need to maintain isolation and social distancing has created a global health crisis that has had an immense impact on the way in which communication with family members in the ICU setting is now temporarily delivered (Kotfis et al. 2020).

The study site ICU has been committed to providing family-centred care where families can spend time at the bedside, actively participate in care should they wish to do so, and receive face-to-face updates and/or family meetings on their family member's condition, treatment and outcome. Under these normal pre-COVID circumstances, family members, as shown here, were anxious, and uncertain, and not fully satisfied with their ICU journey. The lockdown imposed by the government was also reported to have resulted in confusion, frustration, anger, communication gaps, and post-traumatic stress-related symptoms (Holmes et al. 2020).

Family absence at this study site meant that alternative solutions to meeting family member universal need of information were required to be sourced rapidly.

Information is currently delivered via a daily telephone update by the bedside ICU nurse or ICU clinician and/or electronically by near-me video calls. These updates occur even when the patient is sedated or unconscious.

Nurses and medical staff in this ICU were not used to communicating in this way, but the entire team revealed immense adaptability and creative characteristics in trying to maintain the connection between patients, families, and the ICU team. In preparation for assessing the long-term effects associated with this sudden change in communication, inviting patients and family members to the already established critical care out-patient clinic (either in person or via telemedicine) will be important to assess and address any emotional harm. Future studies are needed to explore the psychological impact of family absence on families of patients with COVID 19.

8.6: Personal reflection

Commencing this journey in 2012, I was a senior charge nurse based in ICU who had a passion for structuring family-centred communication. The opportunity to pursue my clinical doctorate allowed me to develop my skills and knowledge by researching and learning the depth of family-centred care. Over the last 8 years, I have not only grown academically, but also personally.

Finalising a clinical doctorate during the COVID pandemic added unforeseen and competing demands; I have worked as a nurse and a student, and have maintained a family. However, I am grateful that I have been supported by the University of Stirling and NHS Forth Valley to create new knowledge and learning locally that will improve the experiences of our ICU families in this study site.

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Appendices

Appendix I: Published Study

Families of patients in ICU: A Scoping review of their needs and satisfaction with care

Aim: To describe published literature on the needs and experiences of family members of adults admitted to intensive care and interventions to improve family satisfaction and psychological well-being and health.

Design: Scoping review

Methods: Several selective databases were searched. English-language articles were retrieved; and data extracted on study design, sample size, sample characteristics and outcomes measured.

Results: From 469 references, 43 studies were identified for inclusion. Four key themes were identified: 1) Different perspectives on meeting family needs; 2) Family satisfaction with care in intensive care; 3) Factors impacting on family health and well-being and their capacity to cope; and 4) Psychosocial interventions. Unmet informational and assurance needs impact on family satisfaction and mental health. Structured written and oral information show some effect in improving satisfaction and reducing psychological burden.

Future research might include family in the design of interventions, provide details of the implementation process and have clearly identified outcomes.

Keywords: Family, intensive care, satisfaction, needs, interventions, anxiety and uncertainty

Introduction

In the UK, 191,016 patients were admitted to the Intensive care unit (ICU) in 2016. This figure rose to 193,813 in 2017 (Scottish Intensive Care Society Audit Group, (SIGSAG) 2016, Intensive Care National Audit and Research Centre, (ICNARC) 2017). With increases in the number of patient admissions to ICU come increases in poorer patient outcomes, for example, 20% of patients die prior to hospital discharge or undergo a prolonged period of recovery (SIGSAG, ICNARC, 2017).

Admission to the ICU is often, although not always, unexpected and the patient's condition is usually unstable (Delva et al., 2002). Many ICU patients are unable to communicate with healthcare staff or participate in decision-making regarding their treatment due to the severity of their illness, delirium or sedation (Mitchell et al., 2009). Consequently, healthcare professionals are increasingly approaching family members to speak for them, and expanding the care and support provided from the patient to their family as well (Al-Mustair et al., 2013). Involving the patient's family in the ICU stage of care is essential to enable healthcare providers to fully deliver person centred care. Often family members who know the patient best are not considered as part of the care team (Paul & Finney, 2015).

Admission to ICU, whether planned or unplanned, however means that family members may suddenly be faced with decision-making and uncertainty regarding their relatives' acute condition and prognosis (Paul & Rattray, 2008). Research suggests they are frequently overwhelmed by feelings of anxiety and worry due to fear of losing their loved one, deterioration of the family structure, concerns about the future, coupled with the stressful technological ICU environment

(Bijttebeir et al., 2001, Delva et al., 2002). Up to 50% of relatives experience emotional distress or anxiety for up to two years after hospital discharge which influences their quality of life and lifestyle (Paul & Rattray, 2008). For these reasons, ICU care and quality measurement should include the families' perspective of whether their needs were met or not, satisfaction with the care process and outcome, and evaluation of interventions to improve their psychological health and well-being (Flaatten, 2012). Current literature primarily focuses on healthcare professionals' knowledge and understanding of family needs. It provides little insight from the perspective of the family as to what their experiences are, how they perceive the care delivered and the impact of having a loved one in ICU. There is limited research describing family experiences whilst in ICU and structured interventions that might support them during the patient's critical illness. The aim of this scoping review is to describe published literature on the needs and experiences of family members of adults admitted to intensive care and interventions to improve family satisfaction and psychological well-being and health.

Method

The method adopted for this review was informed by Arksey and O'Malley (2005) scoping review framework. Scoping reviews are undertaken to examine the extent and nature of research activity in a particular field, to summarise and disseminate research findings and identify gaps in the literature (Arksey & O'Malley, 2005). The suggested steps in a scoping review are to: 1) identify the research questions; 2) identify relevant studies; 3) study selection; 4) chart the data; and 5) collate, summarize and report the results (Arksey and O'Malley, 2005). Scoping reviews do not address issues of quality appraisal but rather they

have the potential to produce a large number of studies with different study designs and methodologies.

Research questions

The research questions posed before the literature search started were as follows:

- 1) What is currently known about family needs and family satisfaction with care.?
- 2) What were the psychological symptoms experienced by family members in the ICU and the interventions available aimed at reducing those symptoms?

Identifying relevant studies and study selection

The search strategy involved searching the following electronic databases: Medline, Cinahl, Embase, Psycho Info, Science Direct and Cochrane library of systematic reviews and Google scholar. The search terms used included: family, intensive care, satisfaction, needs, interventions, anxiety and uncertainty. The search covered the period 1979 – 2017 as the first seminal study in this area was published in 1979. To be included in this review, published studies or prior literature reviews had to include relatives of adult critically ill patients admitted to the intensive care unit. Only published papers published or translated into English were included.

Charting the data

The article selection process is summarised in **Figure 1**. Consistent with the approach proposed by Arksey and O'Malley, (2005), the findings from each paper selected were organised and key themes developed pertinent to the scoping aim

A full list of articles were obtained and screened for duplicates by the lead author. Abstracts were examined to identify publications that met the inclusion criteria for this scoping review and reviewed by lead author. Reference lists of relevant articles and eligible primary research studies or reviews were checked by hand to identify articles not captured by electronic searches.

Collating, summarising and reporting results

To enable a logical and descriptive summary of the results, data were extracted using the following key headings: authors(s), year of publication and title of publication; country of origin; study design; sample size; sample characteristics; intervention type and outcome.

Ethics

Ethical approval was deemed not to be required as this was a scoping review

Results

In total 468 published papers were retrieved. Removing duplicates and screening abstracts and full texts resulted in the inclusion of 43 published articles which included 40 research studies, one systematic review and two literature review (**Figure 1**). The quantitative research studies included four randomised control trials, three quasi experimental studies and 19 cross sectional surveys. The qualitative research included two grounded theory studies and six other studies that employed a qualitative approach although no specific design was specified. A further six studies used a combination of quantitative and qualitative approaches. The papers retrieved were published in journals aimed at the

medical profession (n=21), followed by nursing (n=20), psychology (n=1) and social work (n=1). Most of the studies were conducted in the USA (n=13), followed by Canada (n=4), France (n=4), Denmark/Norway/Sweden (n=4), Hong Kong (n=3), Australia (n=3), Belgium (n=3), Jordan/Iran (n=2), UK (n=3), Germany (n=1), Greece (n=1), Turkey (n=1), Spain (n=1). The settings were specified as general ICUs, which incorporated medical, surgical, neurological and trauma patients (n=35), and neurological ICU (n=5).

Four key themes were identified from the scoping review: 1) Different perspectives on meeting family need; 2) Family satisfaction with care in ICU 3) Factors impacting on family well-being and their capacity to cope and; 4) Psychosocial interventions.

Theme 1 Different perspectives on meeting family need

Under Theme 1 two key areas related to meeting family needs were identified, namely: family' member's perceptions of their needs; and the healthcare team's perceptions of family needs.

Family members' perception of their needs

Four quantitative studies (Molter 1979., Lee & Lau., 2003, Auerbach et a.,l 2005, Omari 2009), three qualitative studies (Bond et al.,, 2003, Fry & Warren, 2007, Keenan & Joseph, 2010) were identified and one literature review (Verhaeghe et al., 2005) explored family members' perceptions of their needs (**Table 1**). All four quantitative studies used the Critical Care Family Needs Inventory (CCFNI), a 45 item self-report questionnaire that assessed family needs within five dimensions: support, comfort, information, proximity and assurance (Molter 1979). The

majority of studies were single centre. Family needs data were obtained during the acute phase of critical illness (first 24 hours to 72 hours). The most important family needs identified were for information and assurance, followed by proximity, comfort and support respectively. A recent literature review concluded that information and assurance appeared to be the greatest universal needs of family members of critically ill patients (Verhaeghe et al., 2005, Al Mustair et al., 2013). Families want timely, clear and understandable information about their relative's medical condition, but without leaving room for unrealistic hope.

There was generally consistency across studies in how the importance of these needs are ranked, although some variations do occur (Lee & Lau, 2003, Auerbach et al., 2005), which were attributed to differences in patient's severity of illness, cultural expectations, differences in ICU practices and healthcare systems (Lee & Lau, 2003, Verhaeghe et al., 2005). Age, gender, relationship to the patient, length of patient stay in the ICU and patient diagnosis were not found to be correlated with family members' ranking of needs (Verhaeghe et al., 2005, Omari 2009).

The qualitative studies of family member's perceptions of need provide a deeper understanding of family needs whilst in the ICU. All qualitative data describe that family members feel the need to create an alliance with healthcare staff and that this had a positive impact on their ability to handle the situation they are being faced with (Bond et al., 2003, Fry & Warren, 2007, Keenan & Joseph, 2010). Families who were confident and trusting in healthcare staff's ability to care for their relative felt more able to leave at night and take care of both themselves and their other family members (Fry & Warren, 2007). Those who perceived a

lack of trust or engagement with healthcare staff describe difficulty in coping, lack of confidence, hesitancy to ask questions and dissatisfaction with care provided (Fry & Warren, 2007). Bond et al., (2003) described that inclusion of family members by the ICU team not only increased their understanding of the gravity of the patient's situation but helped prepare them for their potential care givers role on discharge from hospital.

Healthcare teams perceptions of family needs

Few studies have evaluated the ability of healthcare staff to meet and satisfy the needs of ICU family members. Three single centre quantitative studies (Leung et al., 2000, Kinrade et al., 2010, Ozbayir et al., 2014) and one multicentre qualitative study included only nursing staff (Hinkle et al. 2009) (**Table 1**). Three studies, two of which were multicentre evaluated both medical and nursing staff perspectives of family needs, two using quantitative methods (Bijttebeir et al., 2001, Hinkle et al., 2011) and one mixed methods (Takman & Severinsson, 2006). Healthcare staff ranked the need for information and assurance as the top two important needs in all studies. Yet, despite this, both needs were the most frequently cited by family members as being unmet by healthcare staff (Leung et al. 2000, Hinkle et al., 2009, Omari et al., 2009). Unmet needs were reported to occur because ICU nurses and doctors don't perceive family needs accurately, undervalue their role, and/or fail to sufficiently support the family (Leung et al. 2000, Bijttebeir et al., 2001, Hinkle et al., 2009). The patient's illness severity may also mean that the time available for communication with healthcare staff is limited, and the ability to engage in discussion is compromised by the patient's clinical condition (Bijttebeir et al., 2001). Interestingly, age, gender, academic

qualifications and working experience did not predict the healthcare providers' ranking of needs of the family of the critically ill patient (Takman & Severinsson,2006).

Theme 2 Family satisfaction with care in ICU

Seven studies, four of which were large multicentre studies investigated family satisfaction with care and decision-making in the ICU. Three studies used quantitative methods (Heyland et al., 2002, Hunziker et al., 2012, Hwang et al., 2014), and four were mixed methods studies (Hendrich et al., 2011, Karlsson et al., 2011, Schwarzkopf et al., 2013, Clark et al., 2016). No qualitative studies of family satisfaction with care in ICU were found (**Table 2**). Six of the quantitative studies evaluated family satisfaction using the Family Satisfaction-ICU (FS-ICU) questionnaire and one used the Critical Care Family Satisfaction Survey (CCFSS).

Research study findings suggest that families of the critically ill are highly satisfied with the care their relative receives, especially with aspects of care regarding skill and competence of staff, and the respect given to the patient (Heyland et al., 2002, Hendrich et al., 2011, Hunziker et al., 2012, Schwarzkopf et al., 2013, Hwang et al., 2014, Clark et al., 2016). Families were less satisfied with emotional support, the provision of understandable, consistent information, and coordination of care (Heyland et al., 2002, Hwang et al., 2007, Hendrich et al., 2011, Hunziker et al., 2012, Schwarzkopf et al., 2013, Clark et al., 2016). Families felt more satisfied when clear, honest information was delivered to them in understandable language as this enables them to actively participate in the decision-making process (Heyland et al., 2002, Hunziker et al., 2012, Hwang et al., 2014). One study by Heyland et al., (2002) found completeness of information

was the single most important factor accounting for the variability in overall satisfaction. Families who rated the completeness of information highly were much more likely to be completely satisfied with their ICU experience. In another study, families were less satisfied not by the delivery of information received but by the lack of information received from medical staff (Hwang et al., 2014). When family satisfaction with care was measured using the CCFSS, overall satisfaction with care was high, however, similar to Hwang et al., (2014), dissatisfaction among some family members related to the lack of availability of medical staff for regular meetings (Karlsson et al., 2011).

Reporting on the three open-ended questions in the FS-ICU, three of the six studies provided further knowledge of family member's experiences with care delivery within the ICU (Hendrich et al., 2011, Schwarzkopf et al., 2013, Clark et al., 2016). In the free text responses families expressed the need for better communication with healthcare staff and the need for timely, accurate and up-to-date information about changes in their relative's condition.

Theme 3 Factors impacting on family well-being and capacity to cope

Two key factors were identified in relation to the factors impacting on family well-being and capacity to cope, namely, anxiety and uncertainty

Anxiety

Eight studies examined anxiety in family members of the critically ill (**Table 3**). Seven of these studies adopted quantitative approaches (Pochard et al. 2001, 2005, Delva et al., 2002, Rodriguez & San Gregorio, 2005, Young 2005, Paparringopoulos et al., 2006, Day et al., 2013) and one study a qualitative

approach (Iverson et al., 2014). The majority of studies were single centre. Levels of anxiety in family members were mainly measured 24 to 72 hours after the patient's admission to ICU. The prevalence of anxiety symptoms in these studies ranged from 40% to 73% (Pochard et al., 2005). Risk factors associated with an increase in symptoms of anxiety included being female, a spouse, an unplanned ICU admission, lower educational status, poor sleep pattern, fatigue, lack of regular meetings with medical staff and failing to meet family needs (Pochard et al., 2001, Delva et al., 2002, Pochard et al., 2005, Paparringopolous et al., 2006, Day et al., 2013). Whilst symptoms may reduce over time, Paul & Rattray, (2008) in a recent review of the literature, highlighted that moderate to high levels of anxiety are present for up to 2 years after hospital discharge in relatives providing care after ICU.

Uncertainty

Five qualitative mainly single centre studies explored the uncertainty that families face when a relative is admitted to ICU and how this contributes to feelings of anxiety and inability to cope with the magnitude of the situation (Jamerson et al., 1996, Burr et al., 1998, Johansson et al., 2005, Ågård & Harder, 2007, Iverson et al., 2014) (**Table 3**). Families describe their ongoing uncertainty regarding whether their family member will survive or suffer permanent disability, as well as having the daily fear of complications arising (Johansson et al., 2005). The need to seek out information on the patient's condition and prognosis was a consistent theme in all the studies. Families' felt they needed to be at the bedside at all times; they searched for cues from healthcare staff that indicated an improvement or deterioration in the patient's condition (Burr 1998, Ågård &

Harder, 2007). When these cues were absent, symptoms of anxiety manifest due to the uncertainty of the situation and they sought reassurance from staff that their relative was in safe hands. It was the “not knowing” that was the worst part of their entire ICU experience which often lead to misunderstandings and profound feelings of uncertainty, anxiety and distress until sufficient information was given or obtained (Burr 1998, Ågård & Harder, 2007, Iverson et al., 2014). In one study, Iverson et al., (2014) reported the role of surrogate decision maker amplified family members’ anxiety at an already challenging time; they were afraid that they were making the “wrong” decision on behalf of their loved one.

Theme 4 Psychosocial interventions

Seven studies investigated interventions to improve family needs, family satisfaction with care, and anxiety and depression. These studies included four randomised controlled trials (RCT's) (Azoulay et al., 2002., Jones et al., 2004, Lautrette et al., 2007, Yousefi et al., 2012) (**Table 4**) and three quasi experimental studies (Appleyard et al., 2000, Chien et al., 2006, Mitchell et al., 2009) (**Table 4**). Two of the RCTs examined family satisfaction with care as the primary outcome (Azoulay et al., 2002, Yousefi et al., 2012), whilst two trials investigated post-traumatic stress disorder (PTSD) and symptoms of anxiety and depression as outcomes (Jones et al., 2004, Lautrette et al., 2007). Two quasi experimental studies investigated the effect of needs based interventions on family satisfaction (Appleyard et al., 2000, Chien et al., 2006) and a third study examined respect, collaboration and support (Mitchell et al., 2009).

Overall, a diverse range of interventions were used in these studies with the aim of improving the number of family needs met, improving satisfaction and

psychological well-being. Azoulay et al., (2002) distributed a family information leaflet to supplement standardised family meetings to assess whether it improved their understanding of diagnosis and proposed interventions. The leaflet improved comprehension of diagnosis and treatment but not of prognosis. The authors attributed this to the focus of the leaflet being on diagnosis and treatment and that understanding the prognosis is difficult for families. Satisfaction with care did not significantly differ between the two groups. However, although not statistically significant they reported the family information leaflet did improve satisfaction among those family members with good comprehension. Yousefi et al., (2012) examined whether family satisfaction improved by allocating families with a dedicated ICU support nurse. The intervention was based on “family needs inventory” where the ICU nurses role was to provide accurate explanations and information to families about the patient and their critical illness. Information and explanations were given regarding the ICU environment, equipment and personnel as well as treatment, diagnosis and prognosis. Meetings with the physician and allied health professionals were also facilitated. Satisfaction in the intervention group was significantly increased post intervention. Lautrette et al., (2007) introduced use of a bereavement brochure along with a proactive family conference for relatives of patients in ICU with high likelihood of mortality. They found significantly fewer symptoms of Post Traumatic Stress Disorder (PTSD), anxiety and depression after 90 days. In contrast, Jones et al., (2004) failed to show the provision of general written information around recovery after ICU delivered by nurses in 3 ICUs reduced anxiety, depression and PTSD symptoms at eight weeks and six months after ICU discharge. Some relatives remained anxious and they met criteria for PTSD.

Other studies have looked at the effect of relatives assisting with the provision of care to the patient (Appleyard et al., 2000, Chien et al., 2006, Mitchell et al., 2009). Results from quasi experimental studies suggest better family satisfaction and reduced emotional distress post intervention, compared to the usual care group (Appleyard et al., 2000, Chien et al., 2006, Mitchell et al., 2009). For example, Chien et al., (2006) found that performing needs based training on the patient's family needs assessed on admission to ICU, decreased anxiety and increased their satisfaction. The intervention itself was labour intensive and further research is required to identify which specific aspects of the programme were effective. Further, Appleyard et al., (2000) reported greater family satisfaction regarding comfort needs following the introduction of a volunteer programme in the ICU but no differences were found for the other CCFNI factors, including information, assurance, proximity and support. Notably, the volunteers reported the nurses became more communicative and more concerned about families' needs following the introduction of the intervention. In the third study, Mitchell et al., (2009) reported that encouraging patient's family members to assist in providing care to their relatives significantly improved respect, collaboration, support and overall satisfaction. This study, however, only included the relatives of long term ICU patients with a length of stay greater than 11 days thereby limiting the results to this group.

Discussion

To the best of our knowledge this is the first scoping review to describe published literature on the needs and experiences of family members of adult critically ill

patients and interventions to improve family satisfaction and psychological health and well-being. Forty research studies and three review articles were included in the review.

Family needs were investigated primarily through use of the CCFNI which highlights the most pressing family needs as being for information and reassurance followed by proximity, comfort and support respectively. Families want honest and up to date information delivered daily in understandable terms about their relative's progress, without leaving room for unrealistic hope (Auerbach et al., 2005). They also want to be contacted anytime of the day or night if their relative's clinical condition changes and to be reassured they are receiving the best possible care (Omari, 2009). From their experiences, families felt there was a need to develop a trusting and mutually respectful relationship with healthcare staff and that this helped them adjust to the situation they were faced with (Bond et al., 2003, Fry & Warren, 2007, Keenan & Joseph, 2010).

Fulfilling family needs is important as unmet needs leave family members feeling uninformed, dissatisfied and disenfranchised from clinical decision-making and with the day to day care of their relative (Wall et al., 2007). The ability to meet or satisfy family needs is one of the main challenges that healthcare staff encounter in the ICU. Even if families' needs are known to ICU staff, studies have indicated that these needs are not always met (Leung et al., 2000, Hinkle et al., 2009, Omari, 2009).

To improve the quality of care provided to families assessing families' satisfaction with the patient care delivered, particularly in ICU, is important for several reasons. Firstly, healthcare providers need to develop open collaborative and

supportive relationships with family members to enable them to cope with their distress and speak for the patient. Secondly, the collection of objective data on family satisfaction is desirable in order to assess how well healthcare providers are doing in this area. Data on family satisfaction is measured as a surrogate marker of the quality of their care (Heyland et al., 2001).

Key areas for improvement identified were including the family as part of the ICU team, increasing open communication and assessing and potentially revisiting their level of understanding of the information they have been given (Heyland et al., 2002, Hendrich et al., 2011, Hunziker et al., 2012, Schwarzkopf et al., 2013, Hwang et al., 2014, Clark et al., 2016). Nurses who are in constant close contact with families are in an ideal position to ensure that family information and assurance needs are met. However, according to research, some nurses lack confidence in providing information, often being afraid of not giving the correct information or not providing adequate answers (Soderstrom et al., 2003, Engström & Söderberg, 2007, Stayt, 2007). This is thought to be the case because nurses believe they are educationally underprepared and not sufficiently qualified to give the level of information required (Stayt, 2007, Krimshstein et al., 2011). Medical staff on the other hand have difficulty meeting with families and providing regular information delivered in a way in which families understand (Heyland et al., 2002, Hwang et al., 2007, Hunziker et al., 2012). Poor communication skills, insufficient training, delivering patient rather than family centred care and a lack of time have been attributed to this (Azoulay et al., 2000, Bijttebeir et al., 2001, Moreau et al., 2004).

Several studies highlighted additional factors that impact on family needs being met, and their capacity to cope. Symptoms of anxiety are elevated at the onset of critical illness and the uncertainty of their family members condition exacerbate these symptoms (Pochard et al., 2005). From clinical experience and research, high levels of anxiety and uncertainty result in family members overestimating or underestimating the risks and/or benefits of clinical treatments, impairs comprehension and decision-making capabilities (Azoulay et al., 2000, Pochard et al., 2001). Anxiety therefore has important implications for family members who participate regularly in decisions regarding the care of their relative. Providing timely information, as well as preparing families for transitions in the delivery of care, may minimise the uncertainty and anxiety they experience (Azoulay et al., 2000).

Identifying interventions for supporting family members of the critically ill during the acute phase of their illness are necessary because if their relative survives, they are likely to care for them during a prolonged and often difficult recovery period (Pochard et al., 2005). The components of the interventions reviewed included a range of tools or strategies, for example, family information booklet, bereavement brochure, structured meetings and dedicated nurse support (Appleyard et al., 2000, Azoulay et al., 2002, Jones et al., 2004, Chien et al., 2006, Lautrette et al., 2007, Mitchell et al., 2009, Yousefi et al., 2012).

From the intervention studies reviewed, providing a combination of targeted written and oral information delivered by nursing and medical staff caring for the patient significantly increased satisfaction and reduced anxiety with this reduction being sustained over time (Chien et al., 2006, Lautrette et al., 2007, Yousefi et

al., 2012). Reasons for this pattern is because families were provided with good knowledge about their relative's clinical condition and treatment and contacted through the day either by phone or by attending a family meeting. These phone calls or meetings ensured families received updated information, had an opportunity to get questions answered, and support when difficult decisions needed to be made. Additionally, families conveyed greater satisfaction with needs met if they received information about the ICU environment and equipment either through leaflets or discussions with staff and were involved in care of the patient at the bedside (Lautrette et al., 2007). Thus, not maintaining continuous and multiple methods of communication with the family delivered by the ICU team could account for the lack of positive statistically significant results in the other intervention studies (Azoulay et al., 2002, Appleyard et al., 2002, Jones et al., 2004, Mitchell et al., 2009).

Providing high quality information in a variety of ways ensuring that family members understand the nature of their relative's condition, including diagnosis, prognosis and treatment risks and benefits is crucial for family members to cope with their role as substitute decision-makers (Azoulay et al., 2000, 2001, Bond et al., 2003). Azoulay et al., (2016) suggests that discussions with families open with the question "What is your understanding of what the clinical team expects to happen?" or "What has the team told you about what to expect?" If the answer differs from that of the medical staff, then this is the best place to start to identify the source of the discordance. Intensive care units that are able to support interventions based on meeting family information needs, in addition to reducing psychological burden and increasing satisfaction, will enable each family to provide more support to their relative within the ICU.

Limitations of the review

Only English-language articles were considered for inclusion in this scoping review. As such, this review misses potentially relevant articles written in other languages which primarily covers research conducted in America. Most of the studies in this review involved female family members of the critically ill. The majority of studies obtained data from family members within 24–72 hours of admission to the ICU, which could affect the validity of the data because family members experience intense emotions and stress during these times.

Although experimental studies were identified there were some methodological weaknesses. Most studies were descriptive, non-experimental, single centre studies with small sample sizes, as such their findings may not be generalizable. There was an absence of theory to frame or guide the intervention and each study identified limitations within their study design and outcome measures. Differences in study design, population, the number of samples and methods of intervention make it difficult to compare the results. Several of the studies measured the effect of the interventions in reducing family's anxiety, however, it is difficult to ascertain whether the reduction in anxiety is because of the intervention itself or the level of severity of the patient's illness.

Future research

There is a need for further empirical research to increase understanding of family needs and their perspective of whether their needs were met or not, and the factors that militate against this. Differences in perceptions of need should be identified and examined from the perspectives of family and ICU staff over time. More studies are needed into the effectiveness of interventions in ITU and their core components to help improve family members' satisfaction with care and their

psychological health and well-being. Future research might want to include family in the design of interventions, provide details of the implementation process and have clearly identified outcomes.

Implications for practice

- Family members need for information and assurance are perceived as being the most important needs when their relative is admitted to the ICU. One major clinical implication of these results are that healthcare staff's ability to meet or satisfy these needs are not always achieved.
- Family members of patients who are admitted to ICU experience increased psychological burden, yet few studies were found on the effectiveness of interventions to improve their health and wellbeing.
- Regular structured family meetings using targeted written and oral information are suggested to ensure families receive the informational support required. More research is needed in this area to add to the evidence base on the effectiveness of interventions to support family members in ICU

Conclusion

In conclusion, this scoping review identified four key themes that emerged from the literature. A key finding from this review is that has studies of family need have received most attention and consistently identified the need for more information and re-assurance. However, families' perceived needs were not always met by healthcare staff and this negatively impacted on family satisfaction and their psychological health and well-being. Whilst there is some evidence that interventions based on the provision of appropriate written and oral information in ICU can effectively reduce anxiety and improve satisfaction, more empirical research is needed in this area.

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Appendix II: Data Extraction Sheets

Table 11: Studies of family needs

Author	Aim	Setting	Sample Size	Study Design	Outcome
Alsharari et al. (2019)	To identify the most important needs of the family members of patients admitted in the ICU of four public hospitals in Saudi Arabia,	4 General ICUs in Saudi Arabia	233 family members	Quantitative-CCFNI	The three most important needs identified by the family members were the need for assurance, followed by information, proximity. Family members who had an unconscious/semiconscious relative in the ICU assigned a higher level of importance to information need, compared with those with a conscious relative
Auerbach et al. (2005)	To examine family members perceptions of whether their needs were met in a trauma ICU at both at admission and prior to discharge	1 Trauma ICU in teaching hospital in United States (USA)	40 family members	Quantitative-CCFNI	On Admission-most prominent of unmet needs were information, explanations, and comfortable waiting area. At discharge-tended to show all needs were being met
Bijttebier et al. (2001)	To investigate differences between perceptions of family members, physicians and nurses regarding the needs of relatives of critical care patients.	1 general ICU of a University Hospital in Belgium	200 family members, 38 physicians, 143 nurses	Quantitative-CCFNI	Information emerged as being the most important factor across all three groups. Nurses and physicians underestimated this need.
Bond et al. (2003)	To describe the needs of families of patients with severe traumatic brain	1 neurological ICU in trauma centre USA	7 family members	Qualitative-Exploratory interviews	Content analysis of the interviews identified 4 themes 1.The need to know,

	injury in a neurosurgical ICU				2.The need for consistent information, 3.The need for involvement 4.The need to make sense of the experience.
Coulter (1989)	To explore the needs of family members of patients in ICU from the family's perspective	1 ICU of a teaching hospital England, UK	11 relatives of ICU patients	Qualitative – Grounded theory	Six conceptual categories were developed where a strong theme of “Retaining hope “emerged.
Fry & Warren (2007)	To examine the perceived needs of the critical care family members through their own words	1 general ICU in the USA	15 family members	Qualitative-Descriptive	4 needs were expressed by family members. These needs were seeking Information, trusting the professionals, being a part of the care, and maintaining a positive outlook.
Hinkle et al. (2009)	To describe family members needs of ICU patients identified by family members and nurses.	6 ICU's (4 neurological and 2 surgical) in USA	101 family members and nurses	Qualitative-descriptive approach	Hierarchical cluster analysis identified the 4 themes of Emotional resources and support. Trust and facilitation of needs. Treatment information. Feelings. Family members and nurses differed significantly on three of the four themes.
Hinkle & Fitzgerald (2011)	To identify the needs of relatives of ICU patients: Perceptions of nurses, physicians and relatives	6 ICU's (4 neurological and 2 surgical) in USA	101 family members, 28 physicians and 109 nurses	Quantitative CCFNI	The 3 most important needs statements were for assurance: 1)To have questions answered honestly 2)To be assured that the best care possible is being given to the patient 3)To feel the hospital personnel care about the patient.

Keenan & Joseph (2010)	Identify the needs of family members of ICU patients who have sustained a severe traumatic brain injury	1 neurological ICU in Canada	25 family members	Qualitative Semi Structured Interviews	Key themes identified were: The need to talk about their experience. To receive information about the injury and prognosis. To be supported by professionals in becoming involved in their relative's care.
Kinrade et al. (2010)	To investigate the needs of relatives whose family member is unexpectedly admitted to the ICU and compare them with nurses perspectives of family needs.	1 general ICU in Australia	25 family members, 33 nurses	Quantitative-CCFNI	The importance of the need for information provision and communication between family members and ICU staff was identified of key importance.
Lee & Lau (2003)	To identify the immediate needs of family members in a general ICU	1 general medical, surgical and neurological ICU in Hong Kong	40 family members	Quantitative CCFNI	Reassurance and Proximity-most important unmet needs
Leung et al. (2000)	To identify family members perceptions of immediate needs within 48-96 hours following admission of a relative to critical care	1 general ICU in Hong Kong	37 family members, 45 registered nurses	Quantitative-CCNFI	Top need for families was assurance and for nurses it was information.
Molter (1979)	To Identify the needs of relatives of critically ill patients.	1 general ICU in the USA	40 family members	Quantitative -CCNFI	Top 3 needs were: Assurance, Information and proximity
Omari et al. (2009)	To identify the perceived needs of family members who have a family member admitted to the ICU	6 general ICUs in 3 hospitals in Jordan: Ministry of Health, university hospital, and private hospital.	139 family members	Quantitative-CCFNI	The Assurance and Information subscales were perceived as the most important, but the needs associated with these items were met inconsistently.

Ozbayir et al. (2014)	To compare intensive care nurses and relatives perceptions about intensive care family's needs.	1 general ICU in a teaching hospital in Turkey	70 family members, 70 registered nurses	Quantitative-CCFNI	The CCFNI rankings for the 2 groups were similar for 8 out of the ten most highly ranked items but differed in order. Families ranked assurance and information as key priorities. Nurses ranked proximity, assurance then information.
Takman & Severinsson (2006)	To describe and explore nurses and physicians perceptions of relatives needs	8 medical and surgical ICUs in Norway and Sweden	97 Registered Nurses and 5 Physicians	Quantitative and Qualitative-CCFNI plus 1 open ended item	Qualitative content analysis – Identified 4 categories: - The need to feel trust in the healthcare providers' ability' - The need for ICU and other hospital resources', - The need to be prepared for the consequences of critical illness and 'patients' needs - Reactions in relation to significant others

Table 12: Family satisfaction studies

Author	Aim	Setting	Sample Size	Study Design	Outcome
Clark et al. (2016)	To Measure family satisfaction with care in a medical and surgical ICU	1 general ICU in USA	40 family members	Quantitative/Qualitative FS-ICU with analysis of qualitative questions	Overall, family satisfaction with care and decision-making was good. 50% of family members reported the need for more timely and accurate information. Families less satisfied with waiting room, frequency of communication with medical staff.
Eltaybani and Ahmed (2021)	To examine family members' satisfaction in adult intensive care units.	6 general ICUs in Egypt	213 Family members	Quantitative/Qualitative Critical care family satisfaction study(CCFSS) and semi structured interview	Overall family satisfaction was low, this was related to lower economic status, financial hardship and their relative's deterioration. Content analysis of qualitative data revealed four themes that shaped family satisfaction: aspects of family care, aspects of patient care, organizational and administrative issues and environment.
Ferrando et al. (2019)	To assess family satisfaction, investigate how characteristics of patients and their family members impact on family satisfaction.	20 ICUs in United Kingdom	7019 family members	Quantitative FS-ICU	Overall family satisfaction was high at 80%, satisfaction with care 83%, satisfaction with information 76% and satisfaction with decision-making 73% but varied significantly across adult general ICUs studied and by whether the patient survived ICU
Frivold et al. (2016)	To explore family members satisfaction with care and decision-making during their ICU stay and follow up needs	15 ICUs in Norway	123 family members	Quantitative FS-ICU	Families were satisfied with care but less satisfied with ICU staff's frequency of communication. Satisfaction with care was higher than satisfaction with decision-making. Families were less satisfied with the ICU waiting room

Gerasimou et al. (2013)	To assess family satisfaction in ICU and its association with workload	1 ICU in Greece	106 family members	Quantitative FS-ICU	Overall satisfaction with care was high. Families were more satisfied with level of care compared to decision-making. Higher levels of satisfaction were reported regarding caring by ICU staff, nursing skill and competence, interest and caring given to the family. Families less satisfied with waiting room and atmosphere in department.
Haave et al. (2021)	To describe how the family evaluate their satisfaction with their ICU stay	2 ICUs in Norway	57 family members	Quantitative FS -ICU	Family members were highly satisfied with the nursing and care they received. They were less satisfied with information and support with the decision-making process. Patient survival significantly affected family satisfaction
Heyland et al. (2002)	To determine the level of satisfaction of family members with the care that they and their critically ill relative received	6 ICUs across Canada	624 family members	Quantitative FS -ICU	Majority of respondents satisfied with overall care and decision-making. Greatest satisfaction with nursing skill and competence, compassion and respect and pain management. Least satisfied with frequency of communication and waiting room atmosphere
Hendrich et al. (2011)	To describe the qualitative findings from a family satisfaction survey.	23 ICUs across Canada	880 family members	Qualitative/Quantitative FS-ICU with analysis of qualitative questions	6 themes identified central to family satisfaction; Positive comments were more common for: quality of the staff (66% vs 23%), overall quality of medical care provided (33% vs 2%), and compassion and respect shown to the patient and family (29% vs 12%). Positive comments were less common for: communication with doctors (18% vs

					20%), waiting room (1% vs 8%), and patient rooms (0.4% vs. 5%).
Hunziker et al. (2012)	To determine what factors ascertainable at ICU admission predicted family members dissatisfaction with ICU care	9 ICUs in USA	445 family members	Quantitative FS-ICU	The most strongly associated factors reported by families relate to nursing competence, followed by completeness of information, and concern and caring of patients by intensive care unit staff.
Hwang et al. (2007)	To describe family satisfaction with care in a Neurological ICU and Medical ICU .	1 ICU in USA	124 family members	Quantitative FS-ICU	Less than 60% of ICU's families were satisfied with the frequency of physician communication.
Karlsson et al. (2011)	To describe family members satisfaction with the care provided in a Swedish ICU	1 ICU in Sweden	35 family members	Quantitative/ Qualitative Critical care family satisfaction study (CCFSS)	Family members need for regular information was highlighted. The ICU staff's competence was also seen to be important for family members satisfaction with care
Min et al. (2018)	To describe levels of family satisfaction and determine which key variables correlate with high degrees of satisfaction	3 ICUs in Asia	200 family members	Quantitative/Qualitative FS-ICU with analysis of qualitative questions	Family members were satisfied with the care and decision-making. Placement of a Do not resuscitate or higher severity of illness decreased family satisfaction. ICU waiting rooms were associated with the lowest satisfaction.
Schwarzkopf et al. (2013)	To assess family satisfaction in the ICU and areas for improvement using quantitative and qualitative analyses	4 ICUs in a hospital in Germany	250 family members	Qualitative/Quantitative FS-ICU with analysis of qualitative questions	Overall satisfaction with care and satisfaction with information and decision-making based on summary scores was high. No patient or family factors predicted overall satisfaction, including patient survival

Sundarariajan et al. (2012)	To explore the degree and determinants of satisfaction with family members	1 ICU in Australia	180 family members	Quantitative 10 point questionnaire on family satisfaction developed by researchers	Overall family satisfaction was high, less satisfied with frequency of communication with medical staff.
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Table 13: Studies of psychological outcomes

Author	Aim	Setting	Sample Size	Study Design	Outcome
Ågård & Harder (2007)	To explore and describe the experiences of relatives of critically ill adults	1 neurosurgical and 1 General ICU in Denmark	4 spouses and 3 parents	Qualitative Grounded theory	Relatives were both vulnerable and resourceful simultaneously. They tried to fit in though using 3 strategies 1) Enduring uncertainty 2) Putting self aside 3. Forming personal cues. They needed information all of the time and if not received formed their own personal cues leading to misunderstandings.
Bolosi et al. (2018)	To explore the families' psychological symptoms and their evolution over the 1 st week of patients' ICU stay	1 general ICU in Greece	108 family members	Quantitative Hamilton Anxiety Rating Scale Beck Depression Scale II on days 1 and 7 of patients' ICU admission	Anxiety levels were not significantly different among 2 time points Age, education, closeness of relationship, and APACHE II score were factors associated with anxiety changes
Burr (1998)	To explore family needs and experiences and gain insight into nurse/family roles	4 general ICU in teaching hospitals in Australia	105 family members CCFNI 26 Interviews	Quantitative/Qualitative CCFNI / semi structured interviews	Two major needs emerged from the interviews that are not represented on the CCFNI: The need of family members to provide reassurance and support to the patient; and their need to protect.
Day et al. (2013)	To investigate sleep quality, levels of fatigue and anxiety in families of critically ill adults	1 medical and surgical ICU in Canada	94 family members	Quantitative General Sleep disturbance scale Beck Anxiety Inventory Scale	The most common factor associated with poor sleep was anxiety (43.6%), tension (28.7%) and fear (24.5%). The need for more information and greater

				Lee's Numerical Scale for fatigue	frequency of updates was cited by family members as a possible solution for reducing anxiety and promoting sleep
Delva et al. (2002)	To explore the needs and anxiety of family members of patients admitted to the ICU	1 surgical ICU and 1 medical ICU in Belgium	200 Family members	Quantitative State Trait Anxiety Inventory (STAI) CCFNI	The younger the patient the more anxious the family member was (p=.0048). Females were more anxious than males (p<0.01) and state anxiety was higher with non-planned rather than planned admissions (p<.01). Lower educational level predicted higher anxiety (p<.001). Top two needs identified were for information and assurance
Iverson et al. (2014)	To explore surrogate decision makers challenges	2 general ICUs in USA	34 family members	Qualitative Semi Structured Interviews	Anxiety influenced surrogate decision makers confidence in making decisions. This stress can be minimised by improving communication between these family members and the medical team.
Jamerson et al. (1996)	To describe the experiences of families with a relative in ICU	1 surgical/trauma ICU in USA	20 family members	Qualitative Focus Groups	4 categories of experiences were identified: 1. Hovering is an initial sense of confusion and uncertainty, 2. Information seeking is a tactic used to move out the hovering stage and to identify the patients progress 3. Tracking is the process of observing, analysing and evaluating patient care

					4. Garnering of resources is the act of acquiring what the family members perceive as needed for themselves or their relative. Families experience a sense of uncertainty resolved by seeking information and resources.
Johansson et al. (2005)	To gain an understanding of what relatives experience as supportive when faced with the situation of having a next of kin admitted to ICU	1 general ICU in Sweden	29 family members	Qualitative Grounded theory	The ICU situation for relatives was characterised by uncertainty as to whether the patient would survive or suffer functional impairment, as well as a fear of complications arising
McPeake et al. (2016)	To understand the impact of critical care survivorship on caregivers	1 general ICU in UK	36 Family members	Quantitative Four validated questionnaires the Impact of Events Scale-Revised (IES-R) Hospital Anxiety and Depression Scale (HADS), Carer Strain Index (CSI) Insomnia Severity Index (ISI)	Anxiety was present in 69% of caregivers. Depression was present in 56% of caregivers, with a significant association between carer strain and Depression. Those caregivers who were defined as being strained also had significantly higher Insomnia Severity Index scores than those without carers strain
Paparrigopoulos et al. (2006)	To evaluate the short-term psychological impact on family members of intensive care	2 general ICUs in Greece	32 family members	Quantitative: Centre for Epidemiological Depression scale, the state trait anxiety Inventory (STAI) and the impact event scale.	Symptoms of anxiety, depression and Post traumatic stress common (60.4%, 97% and 81% respectively) at first assessment. On second assessment symptoms decreased but remained high (47%, 87% and 59%). Females and

	patients during their stay in ICU				spouses exhibited higher levels of anxiety.
Pochard et al. (2001)	To determine the prevalence and factors associated with symptoms of anxiety and depression in family members of ICU patients	43 mixed (37 adult and 6 paediatric) ICUs in France	920 family members	Quantitative Hospital Anxiety and Depression Scale (HADS)	Symptoms of anxiety and depression common (69.1% and 35.4 % respectively) among family members visiting patients 3 to 5 days after admission to the ICU. Symptoms of anxiety were independently associated with being the spouse, female, lack of regular meetings with nursing and medical staff symptoms of depression were also associated being the spouse, female sex, contradictions in information.
Pochard et al. (2005)	To determine the prevalence and factors associated with symptoms of anxiety and depression in family members at the end of ICU stay	78 mixed ICUs in France	544 family members	Quantitative Hospital Anxiety and Depression Scale (HADS)	Symptoms of anxiety and depression common (73.4% and 35.3 % respectively) at the end of their ICU stay. Symptoms of depression were more prevalent in non survivors (48.2%) than survivors (32.7%). A high severity of illness and younger patient age on admission predicted both anxiety and depression.
Rodriguez & San Gregorio (2005)	To evaluate whether certain variables (Anxiety, depression, Quality of life) impacted on family members on ICU admission and 4 years later	1 Neurosurgical ICU in Spain	57 family members	Quantitative Psychosocial questionnaire developed by authors Clinical Analysis Questionnaire Family Environment Scale Fear of Death Scale	High anxiety depression, apathy withdrawal and paranoia scores were high during ICU admission compared to scores obtained 4 years later. Relative's scores for "fear of their own death" were lower on ICU

					admission compared to 4 years later.
Wong et al. (2017)	To discuss families' experiences of their interactions when a relative is admitted unexpectedly to the ICU	1 General ICU in Australia	25 family members	Qualitative Grounded theory	Family members found the unfamiliar ICU surroundings, the medical equipment and perceptions of "being kept in the dark" contributed to uncertainty and anxiety.
Young et al. (2005)	To investigate symptoms of anxiety and depression in patients and families after ICU discharge following cardiac surgery	ICU follow up clinic in the UK	15 family members, 20 relatives	Quantitative HADS	Relatives were more anxious than patients. Anxiety and depression scores for family members of planned admissions were less when compared with studies of unplanned admissions

Table 14: Psychosocial Intervention studies

Author	Aim	Setting	Sample Size	Study Design	Outcome
Appleyard et al. (2000)	To gain knowledge and understanding of the role of volunteers pay in the critical care family waiting room	1 general ICU in the USA	58 Family members	Quantitative Quasi-experimental study with pre- and post-test design	Increased family satisfaction from comfort needs only.
Azoulay et al. (2002)	To determine whether a standardized family information leaflet improved satisfaction and comprehension of the information provided to family members of ICU patients.	34 General ICU in France	Family members Intervention Group=87 Control Group = 88	Quantitative A multicentre, prospective, randomised controlled trial (RCT) (Blinded)	Increased family Satisfaction and improved comprehension of information post intervention
Chien et al. (2006)	To examine the effect of a needs-based education programme provided within the first 3 days of patients' hospitalisation, on the anxiety levels and satisfaction of psychosocial needs of their families.	1 General ICU in Hong Kong	Family members Intervention group = 34. Control Group= 32	Quantitative Quasi-experimental with pre- and post-test design.	Significant reduction in anxiety post intervention. Increased satisfaction of family members.
Cox et al. (2018)	To compare effects of a coping skills training (CST) program with an education program on patient and family psychological distress	5 Medical and Surgical ICUs in USA	Family members in the Intervention group=86) Control group=89),	Quantitative Multicentre RCT	No Difference in depression, anxiety or PTSD between groups

Garrouste-Orgeas (2016)	To investigate family perceptions of having a nurse participating in family conferences and to assess the psychologic wellbeing of the same families after ICU discharge	1 General ICU in France	Family members in the intervention group=44, Control group=42	Quantitative Randomised Control trial	Following a planned proactive participation of a nurse in family conferences led by a physician. Significant decrease in depression and anxiety at 3 months for intervention group
Jones et al. (2004)	To evaluate the effectiveness of the provision of information in the form of a rehabilitation program following critical illness in reducing psychological distress in the patients' close family.	3 General ICU in UK	Family members Intervention Group = 56 Control Group =46	Quantitative Randomised controlled trial, blind at follow-up with final assessment at 6 months.	High incidence of psychological distress which did not reduce post intervention
Lautrette et al. (2007)	To evaluate the effect of a proactive communication strategy that consisted of a family conference conducted according to specific guidelines and that concluded with the provision of a brochure	22 (10 medical, 3 Surgical and 9 General) ICUs in France	Family members Intervention Group=56 Control group = 52	Quantitative Multicentre RCT.	Decreased the risk of symptoms of post-traumatic stress disorder, anxiety and depression.
Miller & Courtney (2004)	To investigate whether the introduction of a pre-transfer educational intervention led to a reduction in uncertainty and anxiety	1 general ICU in Australia	Family Members Intervention group=82 Control group=80	Quantitative Quasi-experimental with pre- and post-test design.	Anxiety and uncertainty were high in both groups pre-transfer. Anxiety reduced significantly post transfer in both groups. Uncertainty reduced significantly in the intervention group only. Family uncertainty was significantly related to anxiety. Anxiety increased significantly with reduced social support

Mitchell et al. (2009)	To evaluate the effects on family-centred care of having critical care nurses partner with patients' families to provide fundamental care to patients.	2 General ICUs in USA	Family members Intervention Group= 99 Control Group =75	Quantitative Quasi-experimental with pre- and post-test design.	Improved respect, collaboration, support and overall scores of family-centred care.
Othman et al. (2016)	To test the effectiveness of information booklets on satisfaction with decision-making in critically ill adults	1 ICU in Malaysia	Family members in the intervention group=42 Control group=42	Quantitative Quasi-experimental with pre- and post-test design.	Increased family satisfaction regarding decision-making post intervention.
White et al. (2018)	To evaluate a multicomponent family support intervention against usual care on three outcome domains: long term psychological distress, the quality of decision-making and clinician family communication	5 ICU (2 specialist and 3 general) in USA	Family members intervention group=429 Control group=677	Quantitative Multicentre RCT	The family support intervention delivered by the ICU team did not significantly affect anxiety or post-traumatic stress symptoms
Yousefi et al. (2012)	To determine the effectiveness of nursing interventions based on family needs on family satisfaction level of hospitalized patients in the neurosurgery ICU.	1 neurosurgical ICU in Iran	Family members Intervention group=32, Control group = 32	Quantitative Multicentre RCT	Increased satisfaction of families.

Appendix III: Joanna Briggs Institute Critical Appraisal Checklist for Cross-Sectional Studies



JBI Critical Appraisal Checklist for Analytical Cross Sectional Studies

Reviewer _____ Date _____

Author _____ Year _____ Record Number _____

	Yes	No	Unclear	Not applicable
1. Were the criteria for inclusion in the sample clearly defined?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Were the study subjects and the setting described in detail?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Was the exposure measured in a valid and reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Were objective, standard criteria used for measurement of the condition?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Were confounding factors identified?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Were strategies to deal with confounding factors stated?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Were the outcomes measured in a valid and reliable way?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Was appropriate statistical analysis used?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Overall appraisal: Include Exclude Seek further info

Comments (including reason for exclusion)

Appendix IV Family meeting toolkit “original” (Nelson et al. 2009)

Tool 1 – Family meeting planner

Family meeting planner

Day in ICU Initial of staff documenting in Medical records

Day 0 (day of admission to ICU)

- S/P cardiac arrest
- Advanced malignancy
- Admitted to ICU after ≥ 10 days in hospital
- Admitted to hospital from nursing home
- Age over 80 years with comorbid conditions
- Simultaneous failure of ≥ 3 organ systems
- S/P intracerebral bleed requiring mechanical ventilation
- Other factor(s)

Day 0 Identify family/other surrogate and obtain contact information

Day 0 If patient can comprehend and communicate, discuss involvement of family in meeting with ICU team

Days 0-3 Contact family member(s) to schedule meeting

Days 0-5 Identify and notify staff (MD, RN, SW, Chaplain, Palliative Care clinician) to be present at meeting

Days 0-5 Establish team consensus on meeting goals and prepare agenda

Days 0-5 Conduct interdisciplinary family meeting

Days 0-5 Document meeting using Family Meeting Documentation Temp

Tool 2 – Family Meeting Guide

Family Meeting Guide

Meeting with the ICU team: a checklist to help families prepare

In our ICU, we routinely meet with the family of patients who are admitted to intensive care to talk about the condition and care of your loved one. To make the most of this opportunity, it is helpful for you to give some thought before the meeting to things that you or the team may want to discuss. You can use this checklist to organize your thoughts and prepare questions to ask the ICU team. You may wish to write notes on this sheet (there is additional space on the back) and bring it with you to the meeting.

- Review what you know at this point about the patient's illness and treatments, so that at the meeting you can check if this is correct, complete, and current.

Are you clear about:

- Why the patient was brought to the ICU and what has happened since then
- What the patient's main medical problems are now
- What treatments the ICU is giving or planning to give to the patient
- What the doctors expect will happen
- What other treatment choices are available
- What medical decisions need to be made

Check the topics you want to clarify; you can ask about them at the meeting

- If you have concerns, worries, fears, or other feelings about the patient's condition or something else related to the ICU care, write them down so you can share them at the meeting.

▫ Give the ICU a list of healthcare team members and family members who should come to the meeting if they can. Healthcare team members include:

- ICU doctor in charge
- Another doctor(s) who is important in the patient's care
- Nurse
- Social worker
- Chaplain

▫ Bring to the ICU (if you haven't already) any documents or papers like a healthcare proxy or living will that relate to medical decisions for the patient.

▫ If the patient can't talk to you or the team now, think back to things the patient may have said in the past about ICU treatments—for example, conversations when someone else was seriously ill. Think about what the patient would say at the present time if he or she could talk and make decisions. This may help you and the ICU team to decide on care that is right for the patient.

▫ What are your goals for the ICU meeting?

▫ When the meeting is over, you should feel that the healthcare team members:

▫ Answered your most important questions

▫ Listened to your thoughts and feelings

▫ Explained the situation and the next steps clearly

If something was missing, write it down so you can follow-up with the doctor or nurse.

Tool 3 – ICU Family Meeting Note: template for medical record documentation

Today, --/--/---, at --:-- AM/PM, a meeting took place with the family of (PATIENT). This meeting was necessary for determining the appropriate course of critical care treatment.

Location: The meeting was held in the following location:

- Patient's bedside
- Family meeting room
- Other, specify _____

Patient participation:

- The patient participated in the meeting
- The patient did not participate in the meeting due to
- Lacked capacity (eg, intubated, sedated, comatose)
- Severity of illness or symptom distress
- Other reason why patient was unable or incompetent to participate in providing history

and/or to make treatment decisions, specify

Family participation:

- The patient's surrogate medical decision maker participated
- Legally authorized healthcare proxy
- Other surrogate

Name of this person: _____ Family or other relationship to patient: _____

- Other family members/other individuals were present (identify):

_____, _____,
_____, _____,
_____, _____,

Clinical team participation: The following clinical team members attended this meeting:

- MD _____
- RN _____
- SW _____
- Chaplain _____

Palliative Care Consultant _____

Other _____

Topics of discussion: The following were discussed:

Patient's diagnosis/current condition: (Free text–optional)

Patient's prognosis: (Free text–optional)

Patient/family needs and preferences: (Free text–optional)

Treatment goals/options/decisions: (Free text–optional)

- Review of family's understanding of patient's condition, prognosis, and treatment goals/options/decisions (family was asked to summarize)

Other content of meeting:

- Opportunity given for family to speak and ask questions
- Family was assured of attention to patient comfort
- Family was assured that clinical team will not abandon patient or them, even if critical care treatments are withheld or withdrawn
- Support was provided for informed, good-faith, family decisions
- Emotions expressed by family were acknowledged and addressed

Time involved in meeting:

- Time for discussion to determine the appropriate course of critical care treatment: _____ minutes
- Total duration of meeting: _____ minutes Signed: _____

Appendix V: Research Nurse Protocol

The purpose of the study will be explained in detail to the ICU research nurse, who has been conducting research within the ICU for the past 10 years collecting data for predominantly large multicentre randomised control trials. The following steps will be undertaken by the research nurse.

Step 1

Each weekday in consultation with the nurse in charge potential patients for study inclusion will be screened using the inclusion/exclusion criteria. The screening and recruitment log will be completed to document all patients considered for the study and subsequently included or excluded from the recruitment process and reasons given.

Step 2

In consultation with the ICU healthcare team the key family member for the patient will be identified. Within forty eight hours of the patients admission to ICU, and after they have been stabilised the key family member will be invited to participate in the study. The family member will be given a verbal explanation of the purpose of the study and the information sheet to read then given time to ask questions.

Step 3

Written consent can be obtained up to 48 hours of the patient's ICU admission. This will allow for a 24 hour cooling off period and more time for families to consider their participation at a stressful time in their lives. Once written consent is obtained the identified family member would be asked to complete the three baseline questionnaires in a private family room within ICU. These would be given back to you upon completion and stored within the locked cupboard within the ICU research room. The patient's clinical data which is available at this stage will be inserted into the socio demographic sheet.

The screening log completed in step 1 will identify whether the family member will be allocated to receive the communication strategy (intervention group) or usual care (control group). The group allocation is allocated sequentially.

Step 4

The family member allocated the control group will be informed that they will continue to obtain updates on their family members progress as and when they

require them. The communication between ICU clinicians and these family members will be documented in the family section of the patients ICU medical notes as per normal clinical practice.

The family member allocated to the intervention group will receive a family meeting guide and an explanation of its purpose. At this time a family meeting date can be set with the family member. If not, this can be set at the next patient visit but must be set to allow a meeting to be conducted within 72 hours of the patients ICU admission.

Step 5

Once a family meeting date has been established, complete the family meeting planner with the date of the meeting, relatives contact details and inform the ICU consultant and bedside nurse when the family meeting will take place. After the first meeting the ICU consultant will complete the medical documentation template and place within the family section of the patients ICU medical notes.

Liaise with the family member regarding the date for the next meeting which will occur in 7 days' time unless a change in the patient's condition occurs and a meeting is required sooner. If a meeting is required sooner the date for this meeting and the communication between the families and the ICU clinician will be documented on the planner and medical documentation template as per format in the first meeting.

Step 6

For both the intervention and control group liaise with nurse in charge daily with regards to potential patients in the study being discharged to ward based care. If the patient is being discharged invite the same family member either by telephone or at the next patient visit to complete the same three questionnaires in a dedicated private room within in the ICU. These will be given back to you upon completion and stored within the locked cupboard within the ICU research room. The questionnaires require to be completed prior to ICU discharge and not when the patient is back within the ward.

Step 7

The six questionnaires (3 on admission and 3 on discharge) will be kept together in the locked cupboard of the ICU research room. Once the patient has been discharged their actual length of stay will be documented on the patient's socio demographic sheet.

Appendix VII: Family Socio-demographic characteristics

Please complete the following to help us know a little about you and your relationship to the patient.

1. I am: Male Female

2. I am _____ years old

3. I am the patient's:

Wife Husband Partner Mother Father Sister Brother

Daughter Son Other (Please specify):

4. Before this most recent event, have you been involved as a family member of a patient in an ICU (Intensive Care Unit)? Yes No

5. Do you live with the patient? Yes No

If no, then on average how often do you see the patient?

More than weekly Weekly Monthly Yearly Less than once a year

6. Where do you live? In the city where the hospital is located Out of town

7. What is your nationality?

8. Was your relatives admission to ICU expected or unexpected ? Yes No

Appendix IX: Three validated self-report questionnaires

Key number _____

Patient's initials _____

SELF-EVALUATION QUESTIONNAIRE STAI Form Y-1

Please provide the following information:

Name _____ Date _____ S _____

Age _____ Gender (Circle) M F T _____

DIRECTIONS:

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel *right* now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

NOT AT ALL
 SOMEWHAT
 MODERATELY SO
 VERY MUCH SO

- | | | | | |
|--|---|---|---|---|
| 1. I feel calm | 1 | 2 | 3 | 4 |
| 2. I feel secure | 1 | 2 | 3 | 4 |
| 3. I am tense | 1 | 2 | 3 | 4 |
| 4. I feel strained | 1 | 2 | 3 | 4 |
| 5. I feel at ease | 1 | 2 | 3 | 4 |
| 6. I feel upset | 1 | 2 | 3 | 4 |
| 7. I am presently worrying over possible misfortunes | 1 | 2 | 3 | 4 |
| 8. I feel satisfied | 1 | 2 | 3 | 4 |
| 9. I feel frightened | 1 | 2 | 3 | 4 |
| 10. I feel comfortable | 1 | 2 | 3 | 4 |
| 11. I feel self-confident | 1 | 2 | 3 | 4 |
| 12. I feel nervous | 1 | 2 | 3 | 4 |
| 13. I am jittery | 1 | 2 | 3 | 4 |
| 14. I feel indecisive | 1 | 2 | 3 | 4 |
| 15. I am relaxed | 1 | 2 | 3 | 4 |
| 16. I feel content | 1 | 2 | 3 | 4 |
| 17. I am worried | 1 | 2 | 3 | 4 |
| 18. I feel confused | 1 | 2 | 3 | 4 |
| 19. I feel steady | 1 | 2 | 3 | 4 |
| 20. I feel pleasant | 1 | 2 | 3 | 4 |

SELF-EVALUATION QUESTIONNAIRE

STAI Form Y-2

Name _____ Date _____

DIRECTIONS

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

ALMOST NEVER
SOMETIMES
OFTEN
ALMOST ALWAYS

- | | | | | |
|---|---|---|---|---|
| 21. I feel pleasant..... | 1 | 2 | 3 | 4 |
| 22. I feel nervous and restless | 1 | 2 | 3 | 4 |
| 23. I feel satisfied with myself..... | 1 | 2 | 3 | 4 |
| 24. I wish I could be as happy as others seem to be | 1 | 2 | 3 | 4 |
| 25. I feel like a failure | 1 | 2 | 3 | 4 |
| 26. I feel rested | 1 | 2 | 3 | 4 |
| 27. I am "calm, cool, and collected"..... | 1 | 2 | 3 | 4 |
| 28. I feel that difficulties are piling up so that I cannot overcome them..... | 1 | 2 | 3 | 4 |
| 29. I worry too much over something that really doesn't matter..... | 1 | 2 | 3 | 4 |
| 30. I am happy | 1 | 2 | 3 | 4 |
| 31. I have disturbing thoughts | 1 | 2 | 3 | 4 |
| 32. I lack self-confidence..... | 1 | 2 | 3 | 4 |
| 33. I feel secure | 1 | 2 | 3 | 4 |
| 34. I make decisions easily | 1 | 2 | 3 | 4 |
| 35. I feel inadequate..... | 1 | 2 | 3 | 4 |
| 36. I am content | 1 | 2 | 3 | 4 |
| 37. Some unimportant thought runs through my mind and bothers me | 1 | 2 | 3 | 4 |
| 38. I take disappointments so keenly that I can't put them out of my mind..... | 1 | 2 | 3 | 4 |
| 39. I am a steady person..... | 1 | 2 | 3 | 4 |
| 40. I get in a state of tension or turmoil as I think over my recent concerns and interests | 1 | 2 | 3 | 4 |

Mishel Uncertainty in illness Scale-Family member Form

Instructions: Please read each statement. Take your time and think about what each statement says. Then place a "X" under the column which most closely measures how you are feeling about your family member TODAY. If you agree with a statement, then you would mark under either "Strongly Agree" or "Agree". If you disagree with a statement, then mark under either "Strongly Disagree" or "Disagree". If you are undecided about how you feel about your family member, then mark under "Undecided" for that statement. Please respond to every statement.

1. I don't know what is wrong with my family member.

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

2. I have a lot of questions without answers

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

3. I am unsure if his/her illness is getting better or worse

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

4. It is unclear how bad his/her pain will be

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

5. The explanations they give about my family members seem hazy to me.

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

6. The purpose of each treatment for any family member is clear to me

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

7. I do not know when to expect things to be done to him/her

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

8. His/her symptoms continue to change unpredictably

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

9. I understand everything explained to me

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

10 The doctors say things to me that could have many meanings

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

11. I can predict how long his/her illness will last

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

12. My family members treatment is too complex to figure out

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

13. It is difficult to know if treatments or medications are helping my family member

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

14. There are so many different types of staff, its unclear who is responsible for what

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

15. Because of the unpredictability of my family members illness, I cannot plan for the future

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

16. The course of my family members illness keeps changing. He/she has good and bad days

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

17. Its vague to me how I will manage the care of my family member after he/she leaves hospital

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

18. It is not clear to me what is going to happen to my family member

Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
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	(5)	(4)	(3)	(2)	(1)
19. I usually know if my family member is going to have a good or bad day					
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree	
	(5)	(4)	(3)	(2)	(1)
20. The results of my family members test are inconsistent					
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree	
	(5)	(4)	(3)	(2)	(1)
21. The effectiveness of the treatment is undetermined					
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree	
	(5)	(4)	(3)	(2)	(1)
22. It is difficult to determine how long it will be before I can care for my family member by myself					
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree	
	(5)	(4)	(3)	(2)	(1)
23. I can generally predict the course of my family members illness					
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree	
	(5)	(4)	(3)	(2)	(1)
24. Because of the treatment, what my family member can and cannot do keeps changing					
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree	
	(5)	(4)	(3)	(2)	(1)
25. I'm certain they will not find anything else wrong with my family member					
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree	
	(5)	(4)	(3)	(2)	(1)
26. They have not given my family member a specific diagnosis					
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree	
	(5)	(4)	(3)	(2)	(1)
27. My family members distress is predictable. I know when it is going to get better or worse					
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree	

(5)	(4)	(3)	(2)	(1)
28 My family members diagnosis is definate and will not change				
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

29 I can depend on the nurses to be there when I need them				
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

30 The seriousness of my family members illness has been determined				
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

31.The doctors and nurse use everyday language so I can understand what they are saying				
Strongly Agree	Agree	Undecided	Strongly Disagree	Disagree
(5)	(4)	(3)	(2)	(1)

Family Satisfaction with Care in the Intensive Care Unit©

Key Number _____ Patients Initials _____

FS-ICU (24)

How are we doing?

Your opinions about your family member’s recent admission to the Intensive Care Unit (ICU)

Your family member was a patient in this ICU. You have been recorded as being the “next-of-kin”. The questions that follow ask YOU about your family member’s most recent ICU admission. We understand that there were probably many doctors and nurses and other staff involved in caring for your family member. We know that there may be exceptions but we are interested in your overall assessment of the quality of care we delivered. We understand that this was probably a very difficult time for you and your family members. We would appreciate you taking the time to provide us with your opinion. Please take a moment to tell us what we did well and what we can do to make our ICU better. Please be assured that all responses are confidential. The Doctors and Nurses who looked after your family member will not be able to identify your responses.

PART 1: SATISFACTION WITH CARE

Please check one box that best reflects your views. If the question does not apply to your family member’s stay then check the not applicable box (N/A).

HOW DID WE TREAT YOUR FAMILY MEMBER(THE PATIENT)						
1.	Concern and Caring by ICU Staff: The courtesy, respect and compassion your family member(the patient) was given	1	2	3	4	5
		Excellent	Very Good	Good	Fair	Poor
	Symptom Management: How well the ICU staff assessed and treated your family member’s symptoms.					
2.	Pain	1	2	3	4	5
		Excellent	Very Good	Good	Fair	Poor
3.	Breathlessnes	1	2	3	4	5

		Excellent	Very Good	Good	Fair	Poor
4.	Agitation	1	2	3	4	5
		Excellent	Very Good	Good	Fair	Poor
HOW DID WE TREAT YOU?						
5.	Consideration of your needs: How well the ICU staff showed an interest in your needs	1	2	3	4	5
		Excellent	Very Good	Good	Fair	Poor
6.	Emotional support: How well the ICU staff provided emotional support	1	2	3	4	5
		Excellent	Very Good	Good	Fair	Poor
7.	Co-ordination of care: The teamwork of all the ICU staff who took care of your family member	1	2	3	4	5
		Excellent	Very Good	Good	Fair	Poor
8.	Concern and Caring by ICU Staff: The courtesy, respect and compassion you were given	1	2	3	4	5
		Excellent	Very Good	Good	Fair	Poor
NURSES						
9.	Skill and Competence of ICU Nurses: How well the nurses cared for your family member.	1	2	3	4	5
		Excellent	Very Good	Good	Fair	Poor
10.	Frequency of Communication With ICU Nurses: How often nurses communicated to you about your family member's condition	1	2	3	4	5
		Excellent	Very Good	Good	Fair	Poor
PHYSICIANS (All Doctors, including Residents)						

11.	Skill and Competence of ICU Doctors: How well doctors cared for your family member.	1	2	3	4	5	
		Excellent	Very Good	Good	Fair	Poor	
	THE ICU						
12.	Atmosphere of ICU was?	1	2	3	4	5	
		Excellent	Very Good	Good	Fair	Poor	
	THE WAITING ROOM						
13.	The Atmosphere in the ICU Waiting Room was?	1	2	3	4	5	
		Excellent	Very Good	Good	Fair	Poor	
	FOR Q14 PLEASE READ RESPONSE OPTIONS CAREFULLY						
14.	Some people want everything done for their health problems while others do not want a lot done. How satisfied were you with the <u>LEVEL</u> <i>or amount</i> of health care your family member received in the ICU?	1	2	3	4	5	
		Very Dissatisfied	Slightly Dissatisfied	Mostly Satisfied	Very Satisfied	Completely Satisfied	

**PART 2: FAMILY SATISFACTION WITH DECISION-MAKING
AROUND CARE OF CRITICALLY ILL PATIENTS**

INSTRUCTIONS FOR FAMILY OF CRITICALLY ILL PATIENTS

This part of the questionnaire is designed to measure how you feel about YOUR involvement in decisions related to your family member's health care. In the Intensive Care Unit (ICU), your family member may have received care from different people. We would like you to think about all the care your family member received when you are answering the questions.

PLEASE CHECK ONE BOX THAT BEST DESCRIBES YOUR FEELINGS

INFORMATION NEEDS							
1.	Frequency of Communication With ICU Doctors: How often doctors communicated to you about your family member's condition	1	2	3	4	5	
		Excellent	Very Good	Good	Fair	Poor	
2.	Ease of getting information: Willingness of ICU staff to answer your questions	1	2	3	4	5	
		Excellent	Very Good	Good	Fair	Poor	
3.	Understanding of Information: How well ICU staff provided you with explanations that you understood	1	2	3	4	5	
		Excellent	Very Good	Good	Fair	Poor	
4.	Honesty of Information: The honesty of information provided to you about your family member's condition	1	2	3	4	5	
		Excellent	Very Good	Good	Fair	Poor	
5.	Completeness of Information: How well ICU staff informed you what was happening to your family member and why things were being done.	1	2	3	4	5	
		Excellent	Very Good	Good	Fair	Poor	
6.	Consistency of Information: The consistency of information provided to you about your family	1	2	3	4	5	

member's condition (Did you get a similar story from the doctor, nurse, etc.)	Excellent	Very Good	Good	Fair	Poor	
---	-----------	-----------	------	------	------	--

PROCESS OF MAKING DECISIONS:	
	During your family member's stay in the ICU, many important decisions were made regarding the health care she or he received. From the following questions, pick one answer from each of the following set of ideas that best matches your views:
7.	Did you feel included in the decision making process?
	1 I felt very excluded
	2 I felt somewhat excluded
	3 I felt neither included nor excluded from the decision making process
	4 I felt somewhat included
	5 I felt very included
8.	Did you feel supported during the decision making process?
	1 I felt totally overwhelmed
	2 I felt slightly overwhelmed
	3 I felt neither overwhelmed nor supported
	4 I felt supported
	5 I felt very supported
9.	Did you feel you had control over the care of your family member?
	1 I felt really out of control and that the health care system took over and dictated the care my family member received
	2 I felt somewhat out of control and that the health care system took over and dictated the care my family member received
	3 I felt neither in control or out of control
	4 I felt I had some control over the care my family member received
	5 I felt that I had good control over the care my family member received

10.	When making decisions, did you have adequate time to have your concerns addressed and questions answered? 1 I could have used more time
	2 I had adequate time

	If your family member died during the ICU stay, please answer the following questions (11-13). If your family member did not die please skip to question 14.
11.	Which of the following best describes your views:
	1 I felt my family member's life was prolonged unnecessarily
	2 I felt my family member's life was slightly prolonged unnecessarily
	3 I felt my family member's life was neither prolonged nor shortened unnecessarily
	4 I felt my family member's life was slightly shortened unnecessarily
	5 I felt my family member's life was shortened unnecessarily
12.	During the final hours of your family member's life, which of the following best describes your views:
	1 I felt that he/she was very uncomfortable
	2 I felt that he/she was slightly uncomfortable
	3 I felt that he/she was mostly comfortable
	4 I felt that he/she was very comfortable
	5 I felt that he/she was totally comfortable
13.	During the last few hours before your family member's death, which of the following best describes your views:

1	I felt very abandoned by the health care team
2	I felt abandoned by the health care team
3	I felt neither abandoned nor supported by the health care team
4	I felt supported by the health care team
5	I felt very supported by the health care team

14. Do you have any suggestions on how to make care provided in the ICU better?

15. Do you have any comments on things we did well?

16. Please add any comments or suggestions that you feel may be helpful to the staff of this hospital.

We would like to thank you very much for your participation and your opinions. Please either return your completed survey to the designated person in the.

Appendix X: Relative Information Sheet



Relative Information Sheet

Version 1.2 29th April 2015

Title of Study

Effects of a communication strategy on family members satisfaction with care in critically ill adults: A quasi-experimental study

I invite you to participate in a research study which seeks to improve communication with family members in the Intensive Care Unit. This study is the basis of a Clinical Doctorate in Nursing at the University of Stirling under the guidance of Dr Patricia Thomson.

The purpose of this research

At present we know that families of patients admitted to the intensive care unit are at increased risk of anxiety and at times communication is poor. We are looking into ways to try and improve this by implementing scheduled and structured family meetings and assessing whether these help to reduce the distress and improves satisfaction with the information you receive.

Before you decide whether you agree it is important for you to understand why the research is being done and what it will involve. Please take your time to read the following information carefully.

What will this research involve?

Your participation in this study will involve completing three questionnaires which will take approximately 30 minutes to complete and if you have been asked to also participate in a family meeting to be held within 3 days of your relative's admission and weekly thereafter. The purpose of these meetings is to discuss your relative's progress and answer any questions you may have. There are no additional bloods tests or investigations.

Do I have to agree to taking part?

No. It is up to you to decide whether or not you are happy to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You can withdraw at any time without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your relative's care or any other treatment in any way. If you decide not to participate the care your relative would receive will be the same as the care usually provided in the ICU.

How secure is the information?

The ICU research nurse will distribute the questionnaires which will have a unique 5 digit number on it. None of the information we collect will have any individual identifiable information (i.e. name, date of birth or address). Information will be stored on a secure computer system which can only be accessed by researcher. No publications arising from the research will have any personally identifiable information.

What are the possible disadvantages of taking part?

We are not aware of any disadvantages from taking part. The only thing that is required of you is a short period of your time for completion of the questionnaires. The questionnaires are completed upon

admission and again prior to discharge of your family member. However, should you feel any discomfort or distress completing the questionnaires please contact the research nurse or a member of the ICU healthcare nursing or medical staff. A member of the pastoral care team is also available if you would like to speak to them please inform a member of the healthcare team or the research nurse. If you decide not to participate, your relatives care will not be affected in anyway.

What are the possible advantages of taking part?

Your participation in this study may not directly help you. However, by agreeing to participate you will increase our knowledge and understanding of how to improve communication within the ICU. This provides an opportunity for us in ICU to assess whether you are better informed about your family members ICU stay. It is possible that you may benefit from taking part if you receive an approach that proves helpful. The research may result in:

- 1) Relatives being better informed about their family members ICU stay
- 2) Improved relative satisfaction with communication and overall care.

How long does the research intervention last?

If you have been asked to take part in the family meetings there is no time scale to these meetings and will be guided by the ICU consultant and yourself. The first meeting will take place within the first 72 hours of your relatives admission then weekly until your relative has been discharge. The questionnaires take approximately 30 minutes to complete and will be completed on two occasions, upon admission and prior to discharge of your relative to the general ward. There is no further involvement in the study after your relative is discharge to the general ward

How will the findings of the study be used?

The results of the study will be published in an international nursing journal and presented to national critical care forums. They will also be disseminated to our critical care healthcare team and staff newsletter via email and presented at the weekly education sessions.

Questions or concerns

If you have further questions or are unhappy with how the research has been carried out, please contact:

Principal Investigator:

Pamela Scott– Forth Valley Royal Hospital, Stirling Road, FK5 4WR, Larbert 01324 **567218**

Ms Janice Grant ICU research nurse telephone number is **01324 567213**

Patricia Thomson Clinical Doctorate Supervisor University of Stirling telephone number 01786 466396

Jayne Donaldson, Head of School, University of Stirling telephone number 01786 466345

Thank you for taking the time to read this participant information sheet and considering whether to take part in the study

Appendix XII: Distribution of anxiety, uncertainty and family satisfaction scores by group

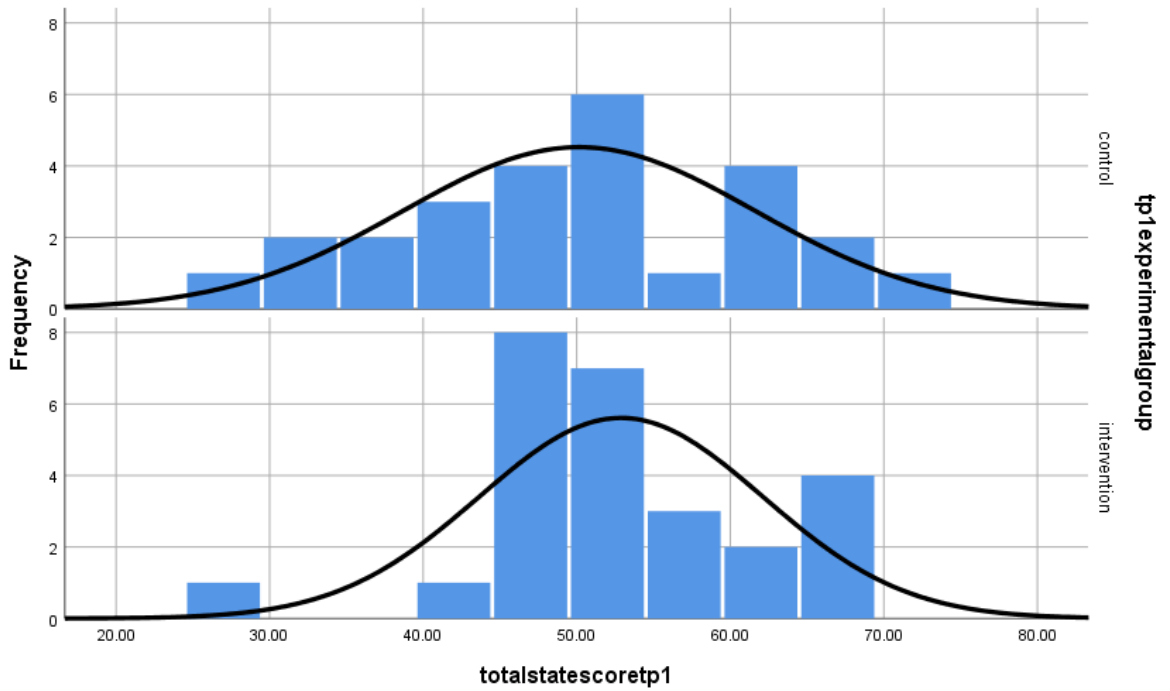


Figure 17: State Anxiety scores distribution by study group at TP1

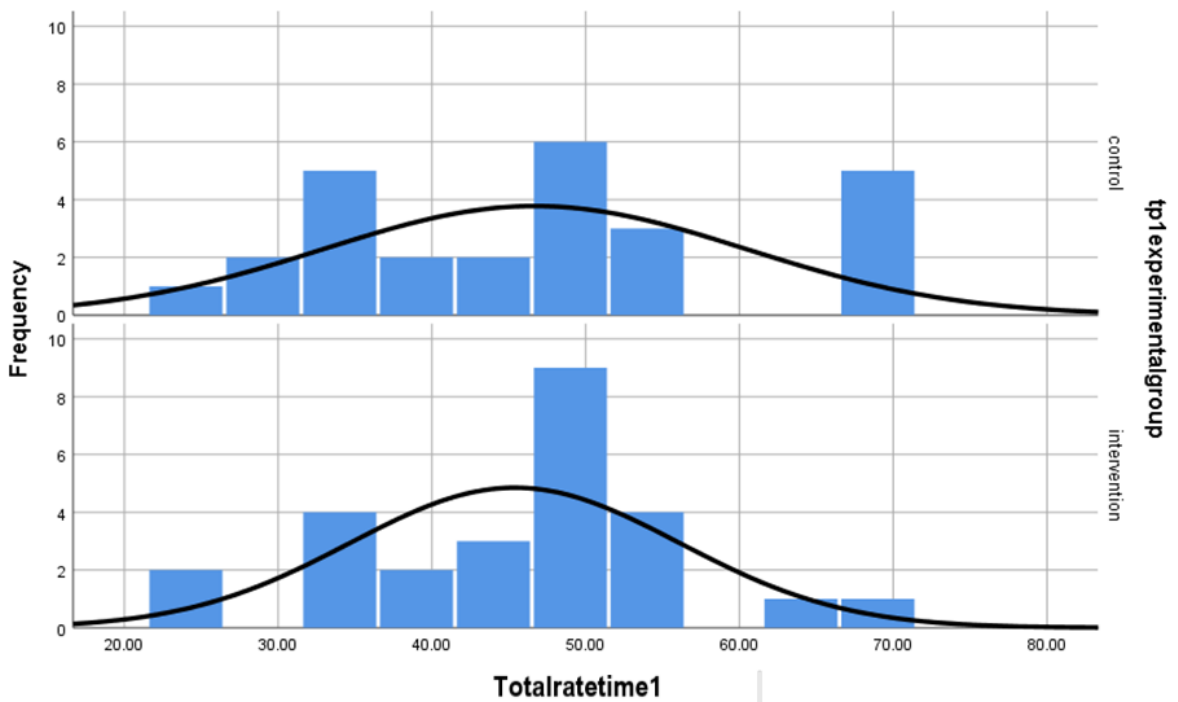


Figure 18: Trait Anxiety scores distribution by study group at TP1

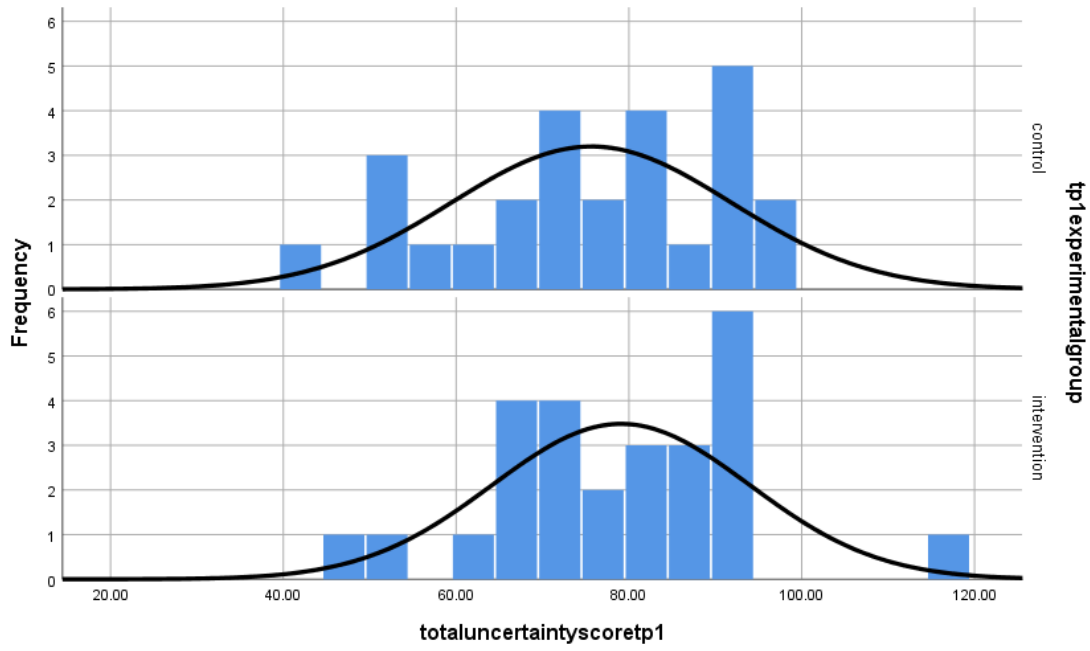


Figure 19: Uncertainty in illness scores distribution by study group at TP1

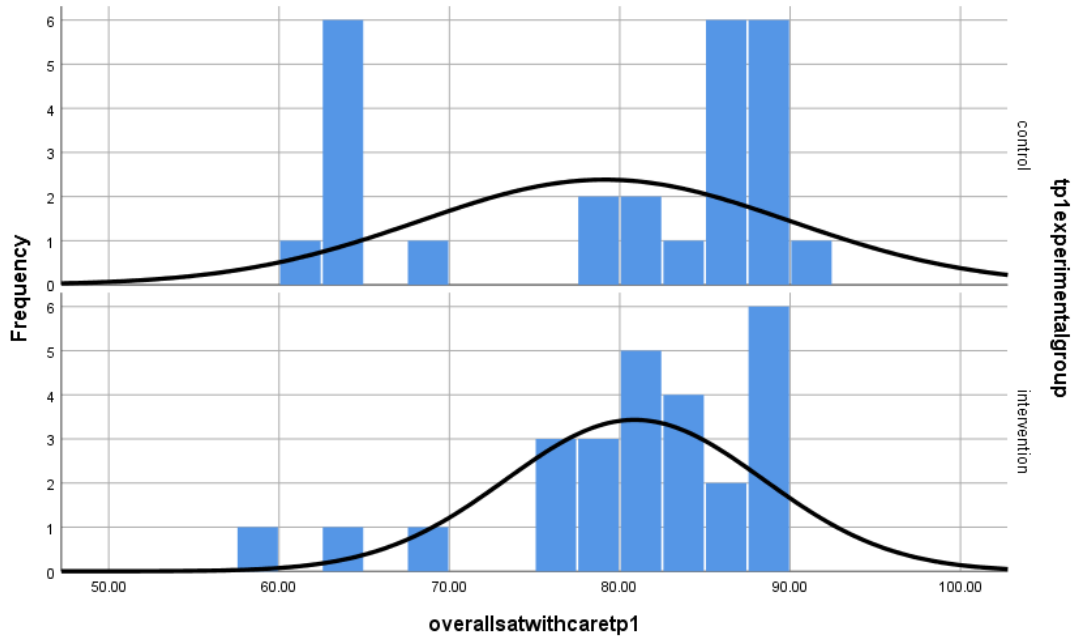


Figure 20: Overall family satisfaction with care scores distribution by study group at TP1

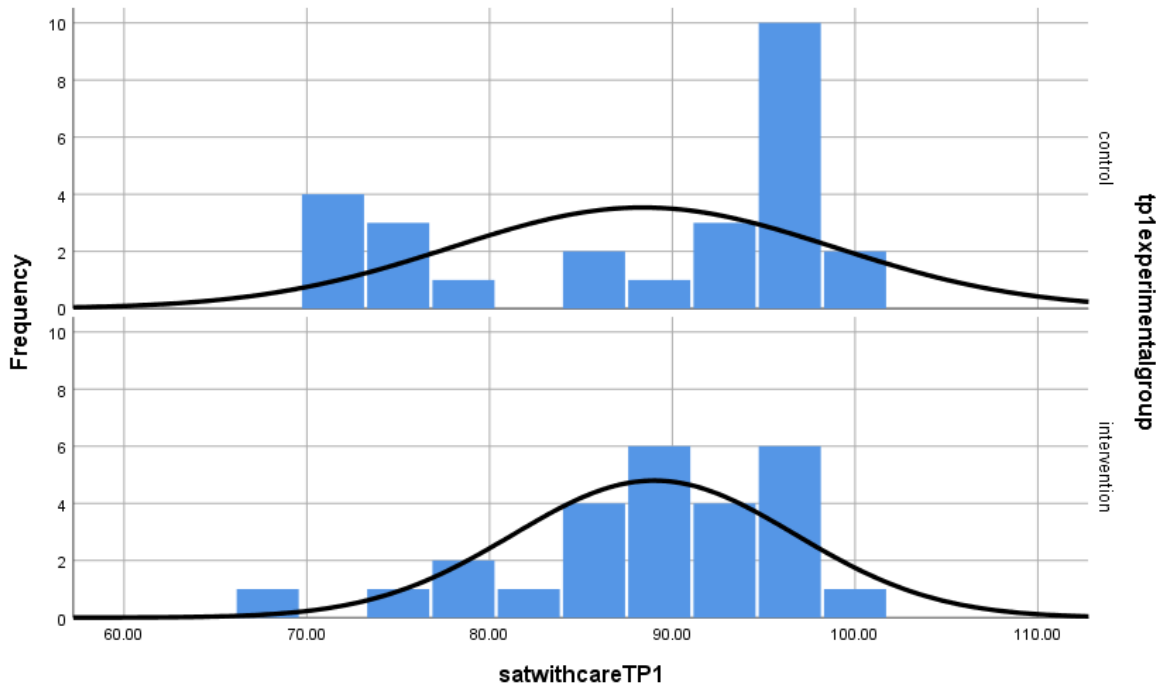


Figure 21: Family satisfaction with care scores distribution by study group at TP1

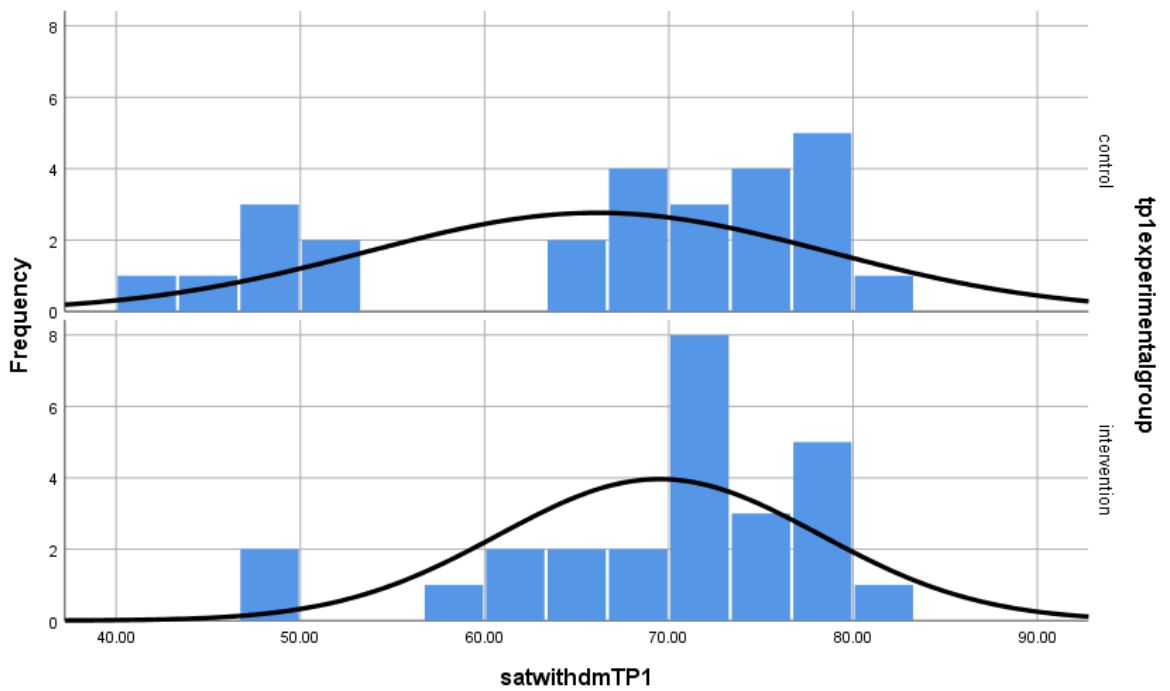


Figure 22: Family satisfaction with information/decision-making scores distribution by study group at TP1

Appendix XIII: NHS Forth Valley R&D Correspondence



Date: 01 June 2016
Your Ref:
Our Ref:
Direct Line: 01324 677564
Email: Allyson.bailey@nhs.net
R&D ref: FV 889

Miss Pamela Scott
Doctoral student University of Stirling/Senior Charge Nurse ICU
Forth Valley Royal Hospital
ICU Forth Valley Royal Hospital
Stirling Road
Larbert
FK5 4WR

Dear Miss Scott

Study title: Increasing family satisfaction with care: The effects of a structured communication strategy in families of critically ill adults.
NRES number: 16/WS/0055

Following the favourable opinion from the West of Scotland Research Ethics Committee 3 on 1 April 2016, I am pleased to confirm that I formally gave Management Approval to the study above on 1 June 2016.

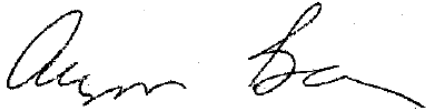
This approval is granted subject to your compliance with the following:

1. Any amendments to the protocol or research team must have Ethics Committee and R&D approval (as well as approval from any other relevant regulatory organisation) before they can be implemented. Please ensure that the R&D Office and (where appropriate) NRS are informed of any amendments as soon as you become aware of them.
2. You and any local Principal Investigator are responsible for ensuring that all members of the research team have the appropriate experience and training, including GCP training if required.
3. All those involved in the project will be required to work within accepted guidelines of health and safety and data protection principles, any other relevant statutory legislation, the Research Governance Framework for Health and Community Care and IHC-GCP guidelines. A copy of the Framework can be accessed via the Chief Scientist Office website at: <http://www.eso.scot.nhs.uk/Publications/ResGov/Framework/RGFEdTwo.pdf> and ICH-GCP guidelines may be found at <http://www.ich.org/LOB/media/MEDIA482.pdf>
4. As custodian of the information collected during this project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT security policies, until the destruction of this data.
5. You or the local Principal Investigator will be required to provide the following reports and information during the course of your study:
 - A progress report **annually**

- Recruitment numbers on a **monthly** basis (if your study should be added to the NIHR research Portfolio you will receive a separate letter from the R&D Office detailing the steps to be taken)
- Report on SAEs and SUSARs if your study is a Clinical Trial of an Investigational Medicinal Product
- Any information required for the purpose of internal or external audit and monitoring
- Copies of any external monitoring reports
- Notification of the end of recruitment and the end of the study
- A copy of the final report, when available.
- Copies of or full citations for any publications or abstracts

The appropriate forms will be provided to you by the Research and Development office when they are needed. Other information may be required from time to time.

Yours sincerely



Pp
MISS TRACEY GILLIES
Medical Director

Appendix XIV: West of Scotland Research Ethics Service Correspondence

WoSRES
West of Scotland Research Ethics Service

NHS
Greater Glasgow
and Clyde

West of Scotland REC 3
West of Scotland Research Ethics Service
West Glasgow Ambulatory Care Hospital
(former Royal Hospital for Sick Children Yorkhill)
Dalmair Street
Glasgow G3 8SW
www.nhsggc.org.uk

Miss Pamela Scott
Doctoral student University of Stirling/Senior
Charge Nurse ICU
Forth Valley Royal Hospital
ICU Forth Valley Royal Hospital
Stirling Road
Larbert
FK5 4WR

Date 1st April 2016
Your Ref
Our Ref
Direct line 0141 232 1805
E-mail WOSREC3@ggc.scot.nhs.uk

Dear Miss Scott

Study title:	Increasing family satisfaction with care: The effects of a structured communication strategy in families of critically ill adults.
REC reference:	16/WS/0055
IRAS project ID:	171941

Thank you for your letter of 23 March 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Statistician.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Liz Jamieson, wosrec3@ggc.scot.nhs.uk.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Appendix XV: University of Stirling Sponsorship



UNIVERSITY OF
STIRLING

STIRLING FK9 4LA SCOTLAND

Carol Johnstone
Research Development Manager
RESEARCH & ENTERPRISE OFFICE
Tel: 01786 466690
Fax: 01786 466688
E-mail: carol.johnstone@stir.ac.uk

7 January 2016

To Whom It May Concern

Research Study: Increasing satisfaction with care in families of critically ill adults

I am pleased to confirm that the University of Stirling will undertake the role of sponsor as outlined in the Research Governance Framework for Health and Community Care for the project entitled "Increasing satisfaction with care in families of critically ill adults", Chief Investigator Pamela Scott, School of Health Sciences, University of Stirling.

Yours sincerely

Carol Johnstone
Research Development Manager

Appendix XVI: Caldicott Approval

0A00000259

NHS FORTH VALLEY
CALDICOTT / DATA PROTECTION CONSENT FORM



APPROVAL FOR THE RELEASE OF NON-ANONYMISED INFORMATION WITHOUT CONSENT

Data Source [enter details of system]: Ward Watcher
Reason for Request: Research Study as part of clinical doctorate in nursing
Time Period for request: Start Date: January 2016 End Date:

Intended Recipients Details	
Name:	Pamela Scott
Position:	Senior Charge Nurse Icu/Clinical doctorate Student
Organisation:	Forth Valley Royal Hospital
Address:	Stirling road Larbert FK5 4WR
Tel. No:	01324 567223
Email Address:	Pamela.Scott3@nhs.net
Data Protection Registration No.	
Name(s) of any co-user(s):	
Data Remaining within UK:	Yes <input checked="" type="checkbox"/> No <input type="checkbox"/>

Will the Data be transferred out with the European Economic Area (EEA) at any time:
Yes <input type="checkbox"/> No <input checked="" type="checkbox"/>
Give Reason for transfer out with EEA:

Nature of Information
Information Requested (specific details required): 1) Patient length of stay (L.O.S) 2) Patients risk of morbidity (APACHE II) score

- 1 -

Appendix XVII: Adapted family meeting toolkit

Tool 1 – Family Meeting Planner (Adapted)

Family meeting planner	
Day in ICU	Initial of staff completing
Day 0	
(day of admission to ICU)	
• Identify key family member and obtain contact information	
Name _____	Relationship to patient _____
Telephone Number _____	
Day 0-3	
• Contact family member(s) to schedule meeting	
• Establish team consensus on meeting goals and prepare agenda	
• If patient can comprehend and communicate, discuss involvement of family in meeting with ICU team	
• Conduct interdisciplinary family meeting (no later than day 3)	
• Document meeting using Family Meeting Documentation Temp	
Dates of Subsequent Meetings	
1) _____	2) _____ 3) _____ 4) _____
5) _____	6) _____ 7) _____ 8) _____

Tool 2 – Family Meeting Guide (Adapted)

Family Meeting Guide

Meeting with the ICU team: a checklist to help families prepare

In our ICU, we routinely meet with the family of patients who are admitted to our critical care to talk about the condition of your loved one. To make the most of this opportunity, it is helpful for you to give some thought before the meeting about the things that you may want to discuss. You can use the checklist to help organize your thoughts and prepare questions to ask the ICU team. You may wish to write notes on this sheet (there is additional space on the back) and bring it with you to the meeting.

Review what you know at this point about your loved one's illness and treatments, so that at the meeting you can check if this is correct, complete, and current.

Are you clear about:

- Why the your relative was brought to the ICU and what has happened since then
- What their main medical problems are now
- What treatments the ICU is giving or planning to give to your relative
- What the doctors expect will happen
- What other treatment choices are available
- What medical decisions need to be made

Check the topics you want to clarify; you can ask about them at the meeting.

- If you have concerns, worries, fears, or other feelings about the relatives condition or something else related to the ICU care, write them down so you can share them
- If your relative can't talk to you or the team now, think back to things the patient may have said in the past about ICU treatments—for example, conversations when someone else was seriously ill.

Think about what the patient would say at the present time if he or she could talk and make decisions. This may help you and the ICU team to decide on care that is right for the patient.

When the meeting is over, you should feel that the ICU team members:

- Answered your most important questions
- Listened to your thoughts and feelings
- Explained the situation and the next steps clearly

If something was missing, write it down so you can follow-up with the doctor or nurse.

Tool 3 – ICU Family Meeting Note: template for medical record documentation

Today, ----/----/—, at ----:---- AM/PM, a meeting took place with the family of (PATIENT)_____.

This meeting was necessary for determining the appropriate course of critical care treatment.

Location: The meeting was held in the following location:

- Family meeting room
- Other, specify _____

Patient participation:

- The patient participated in the meeting
- The patient did not participate in the meeting due to (e.g., intubated, sedated, comatose)

Family participation:

Name of this person: _____ Relationship to Patient _____

- Other family members/other individuals were present (identify): _____, _____, _____, _____

Clinical team participation: The following clinical team members attended this meeting:

- ICU consultant _____
- Staff Nurse _____ Other _____

Topics of discussion:

- Review of family's understanding of patient's condition, prognosis, and treatment goals/options/decisions (family asked to summarize)
- Patient's diagnosis/current condition:
- Patient's prognosis:
- Treatment goals/options/decisions:
- Discuss patient/family needs and preferences
- Re-evaluate families understanding of the patient's condition, prognosis, and treatment goals/options/decisions (ask to re-summarise)

Additional information

Other content of meeting:

- Opportunity given for family to speak and ask questions
- Family was assured of attention to patient comfort

Signed: _____ Title_____